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ABSTRACT

The book presents information for parents of children and young adults with cancer. The first section outlines aspects of the disease itself and considers characteristics of leukemia and solid tumors. Hospitalization and such treatments as chemotherapy and radiation are considered. Common health issues (including diet, dental care, bleeding, and transfusions) are dealt with. The final part of the first section of the handbook details tips for clinic visits and medical procedures, when to call the doctor, and a number of common medical procedures (such as biopsy, scans, and bone marrow aspiration). The second section focuses on coping with cancer. Individual chapters address the following topics (sample subtopics in parentheses): dealing with the diagnosis (telling the child, telling the siblings); continuing life (school, discipline, adolescence, finances); and sources of information, support, and assistance. Also included are a glossary, a bibliography, a list of additional reading materials, and a fold-out drug chart. (CL)

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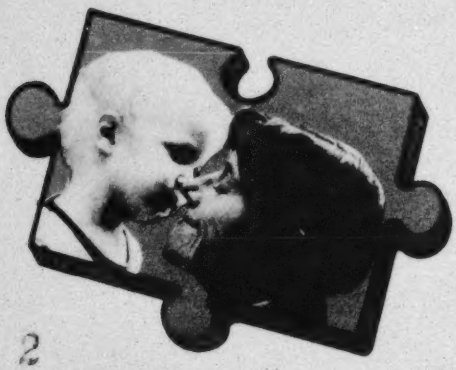
Young People with Cancer

A Handbook for Parents



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health

Young People with Cancer

A Handbook for Parents

Office of Cancer Communications
National Cancer Institute
and
National Candlelighters Foundation

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Although many people have played a role in the development of this handbook, the most important contribution has come from those it is intended to serve—from the parents and family members of young cancer patients, the patients themselves, and from the caregivers who treat them. During the time that the National Cancer Institute's Office of Cancer Communications has made a concentrated effort in the area of coping with childhood cancer, these people have given freely of their time, experience, and expertise.

This publication has benefited from the wealth of information provided through the Candlelighters Foundation and the parents' groups in its communication system, the review and assistance of professionals who treat young people with cancer, and the insights, review, and openness of young cancer patients and their parents. Although they are too numerous to name, their contributions are gratefully acknowledged.

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Foreword

The outlook for the survival of children with cancer has improved dramatically in recent years. Childhood cancer was once considered a swift and certain killer. Today, treatment techniques capable of producing disease-free states (remissions) have increased the length of survival and, in some cases, brought about apparent cures.

Although childhood cancer in general can be viewed as a chronic, treatable illness, it is life-threatening. Treatment efforts are not always successful, and children with cancer and their families may live with uncertainty and the fear of death.

Treatment for childhood cancers is aggressive, and demands much of patients and those who provide them with support and comfort. These demands are both physical and emotional and are disruptive on many levels. For the parents of young people with cancer it is necessary to face their own fears while providing support to their sick child and to healthy brothers and sisters. They must strive to continue life in as normal a manner as possible in an abnormal situation. In their efforts, they are aided by the staff at treatment centers, by other parents, and by family members and friends, but still the primary responsibility is theirs as parents.

This book attempts to provide parents with information on the most common types of cancer, on treatments and side effects, and on the common issues that arise when a child is diagnosed with cancer. It contains medical information and practical tips gathered from the experience of others. Our aim is that this book will be of use to you and other family members in understanding the medical side of cancer and its treatment and in coping with the changes this brings to your daily life.

Director
National Cancer Institute

Introduction

This handbook was written for you—a parent of a young person with cancer. It addresses some of the most common questions about cancer in the young, combining medical information with practical suggestions. Special consideration is given to the emotional impact of cancer on patients and family members. This handbook is designed to help you cope with the stress of a chronic disease that entails rigorous treatment, frequent visits to the doctor and hospital, interruptions in schooling and social activities, physical change, and perhaps most frightening of all, uncertainty about the future.

Since cancer in adults and children actually involves over 100 distinct diseases and since no two patients or families are alike, this handbook cannot address every issue or situation that will arise. Instead, it provides a general guide to childhood cancer: what to expect from it and how to deal with it.

Direct specific questions to your family physician and/or other members of the treatment team. If you want more information in special interest areas, you may be interested in obtaining a book or pamphlet mentioned in the list of additional reading materials beginning on page 79.

The terms used in this handbook are those used by treatment team members when talking about your child's disease or treatment. Some of these may at first be unfamiliar to you. The glossary defines terms used in the handbook and others that might be used by your child's doctor or others involved in his* care.

* To enhance readability, masculine pronouns are used throughout this handbook in statements that apply to members of both sexes.

The Disease

Cancer is actually a group of diseases, each with its own name, its own treatment, and its own chances of control or cure. It occurs when a particular cell or group of cells begins to multiply and grow uncontrollably, crowding out the normal cells. Cancer may take the form of leukemia, which develops from the white blood cells, or solid tumors, found in any part of the body.

Despite considerable and continuing research, no one knows why children get cancer. Some common misconceptions about cancer are addressed below:

1. So far as scientists have been able to determine, nothing you or your child did or didn't do caused the disease. Cancer in children is still a largely unexplained disease, and there is no evidence that you could have prevented it.

2. Few cases of childhood cancer are due to genetic (inherited) factors.

3. In almost all cases of childhood cancer, its appearance in one child does not mean that a brother or sister is more likely to develop it.

4. Cancer is not contagious. It cannot be spread from person to person like a cold, nor from an animal to a person.

5. No food or food additive has been implicated as a cause of any childhood cancer.

Leukemia

Leukemia is a cancer of the blood and develops in the bone marrow, the body tissue that produces blood cells. The bone marrow is a jelly-like substance that fills the inside of the bones.

The bone marrow makes three kinds of cells:

1. *(erythrocytes),*
They give the blood its red color. These cells pick up oxygen and carry it to the tissues. They are also known as RBCs.

2. *(thrombocytes),*
They help stop bleeding if there is injury.

3. *(leukocytes),*
They fight infections. They are also known as WBCs. Leukemia develops from these blood cells. In leukemia, certain white blood cells escape the normal control mechanisms that direct their maturing. Instead of aging so they are able to assume certain functions, they remain young and continue to multiply. This can happen to any of three main kinds of white blood cells:

a. Neutrophils, which eat bacteria
b. Lymphocytes, which make substances to fight bacteria
c. Monocytes, which destroy foreign materials

What is a Blast?

When speaking about leukemia, "blast" is the short name used for lymphoblasts, the immature white blood cells. There are normal blasts and leukemic blasts. Normally, blasts comprise less than 5 percent of the cells made by the bone marrow, and grow to form mature white blood cells with certain typical features visible under the microscope. Leukemic blasts are abnormal since they remain

immature and do not function like mature white blood cells. In many cases they look different from normal blasts when viewed under a microscope.

What Happens in Leukemia?

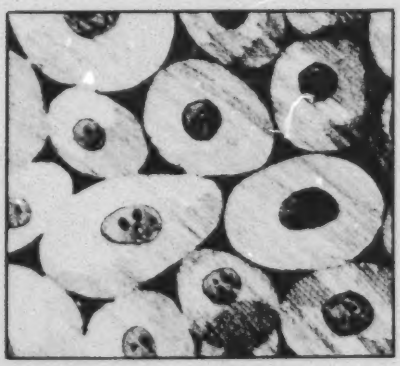
When a large number of blasts (leukemic cells) appear in the bone marrow, several things happen. As the leukemic blast cells accumulate in the bone marrow, they begin to crowd out the normal blood cells that develop there. Eventually, they take up so much room that red blood cells, platelets, and normal white blood cells cannot be produced. When that happens, the young person develops symptoms indicating that normal blood cells are not being manufactured in adequate numbers:

- If red blood cells are crowded out by leukemic cells, the blood will look thin, which makes the patient look pale. The young person also may be tired, since the thin blood cannot carry enough oxygen to the heart, lungs, and muscles.

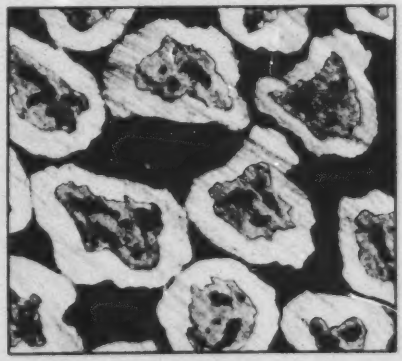
- If blood platelets are crowded out in the bone marrow, the young person may have bleeding problems and unusual bruising.

- If the normal, mature kind of white cells known as neutrophils are crowded out by the blasts, there will be no cells to combat bacteria, and infections may occur.

In some cases, leukemic blasts may spill over from the bone mar-



Normal cells



Cancer cells

row into the blood, where they can be seen by microscopic examination. This may cause a rise in the number of white cells in the blood (the white blood cell count). In other cases, only a few blasts appear in the blood and the white cell count does not change much. When leukemic blasts are present in the blood, they may be carried to other places in the body and enter various body organs. Sometimes they grow in these organs as well as in the bone marrow.

Kinds of Leukemia in Young People

Leukemia is not just one disease. There is actually a type of leukemia for each of the three major kinds of white blood cells—neutrophils, lymphocytes, and monocytes.

Leukemia in any one person can affect only one kind of blood cell. The most common kinds of leukemia are lymphocytic (also called lymphoblastic or lymphoid) and myelogenous (also called granulocytic, myelocytic, myeloblastic, or myeloid). Other types (monocytic, myelomonocytic, progranulocytic, or erythroleukemia) are very rare, but still act much like the more common kinds.

If leukemia affects a young person quickly, it is called "acute" because it comes on suddenly and progresses rapidly without treatment. Almost all childhood leukemias are acute, but the disease is sometimes of the "chronic" type. In chronic leukemia, the bone marrow is able to produce a good number of normal cells as well as leukemic cells so that, compared to acute leukemia, the actual disease course is milder for a period of time. Even without treatment, the disease usually progresses more slowly.

Acute Lymphocytic Leukemia

Acute lymphocytic leukemia (ALL for short) is commonly known as "childhood leukemia." It is the most common leukemia among the young and is the most commonly occurring cancer in children. As its name suggests, it affects the lymphocytes. Most children are between 2 and 8 years old when diagnosed but the disease can occur in people in their twenties and thirties as well. For reasons yet to be understood, slightly more boys get ALL than girls, and it occurs more frequently among white children than black children.

Acute Myelogenous Leukemia

Acute myelogenous leukemia (AML) is also called acute granulocytic leukemia. It usually occurs in people over 25, but sometimes

is found in teenagers and children. In AML, the leukemic blasts develop from the stem cells that would normally give rise to neutrophils. The characteristics of the blasts in AML are generally similar to those of acute lymphocytic leukemia but special tests can be done to help determine whether a leukemia is myelogenous or lymphocytic.

Chronic Myelogenous Leukemia

Chronic myelogenous leukemia (CML) is not common in children. CML's distinguishing feature is the presence of very large numbers of immature neutrophil cells, which seem to mature more efficiently than blast cells. The progression of CML varies greatly, sometimes changing to a type of acute myelogenous leukemia.

Diagnosis and Treatment

Diagnosis of leukemia requires blood tests and examination of the cells in the bone marrow, because early symptoms can mimic many other diseases including mononucleosis, anemia arising from other causes, tonsillitis, rheumatic conditions, meningitis, mumps, and other kinds of cancer.

In any acute leukemia, it is necessary to determine which type of white blood cell has become leukemic, as treatment and response to it are different for each kind. Usually the type of leukemic cell involved can be determined from its appearance under the microscope, but sometimes special tests of the chromosomes and cell chemistry are needed to be completely certain. In rare instances, the cells are too young to be classified. Such cases are called acute stem cell leukemia or acute undifferentiated leukemia (AUL). Other tests such as X-rays and lumbar puncture may also be undertaken to determine if areas other than the bone marrow are involved.

The primary treatment for leukemia is combination chemotherapy, where two or more anticancer medications are used to control or eradicate the disease. Radiation, platelet and red cell transfusions, antibiotic therapy, and occasionally surgery (for unusual complications) are also a part of many treatment programs. In some forms of leukemia, bone marrow transplantation is attempted.

Solid Tumors

What is a Solid Tumor?

The word tumor does not always imply cancer. Some tumors (collections of abnormally growing cells) are benign (not cancerous). When discussing tumors that are malignant (cancerous), however, the term solid tumor is used to distinguish between a localized mass of tissue and leukemia. (Leukemia is actually a type of tumor that takes on the fluid properties of the organ it affects—the blood.)

Different kinds of solid tumors are named for the type of cells of which they are composed:

Sarcomas

Cancers arising from connective or supporting tissues, such as bone or muscle.

Carcinomas

Arise from the body's glandular cells and epithelial cells, which line body tissues.

Lymphomas

Cancers of the lymphoid organs, such as the lymph nodes, spleen, and thymus, which produce and store infection-fighting cells. These cells also occur in almost all tissues of the body, and lymphomas therefore may develop in a wide variety of organs.

Kinds of Solid Tumors in Young People

Lymphomas

Lymphomas are cancers of the lymphatic tissues, which make up the body's lymphatic system. This system is a circulatory network of:

- vessels carrying lymph (an almost colorless fluid which arises from many body tissues).
- lymphoid organs such as the lymph nodes, spleen, and thymus that produce and store infection-fighting cells.
- certain parts of other organs such as the tonsils, stomach, small intestine, and skin.

Lymphomas have been broadly divided into Hodgkin's disease and non-Hodgkin's lymphomas, which include a number of diseases. Hodgkin's disease tends to involve peripheral lymph nodes (those near the surface of the body), where the first sign of disease may be a painless swelling in the neck, armpit, or groin. Hodgkin's disease occurs most commonly in patients in their twenties and thirties and occasionally in adolescents; it is rare in younger children.

In children, non-Hodgkin's lymphomas most frequently occur in the bowel, particularly in the region adjacent to the appendix, and in the upper midsection of the chest, a site where Hodgkin's disease may also occur. An initial sign of disease in these cases may be abdominal pain or swelling, or breathing difficulties and sometimes difficulty in swallowing or swelling of the face and neck. Non-Hodgkin's lymphomas may also occur in other organs, including the liver, spleen, bone marrow, lymph nodes, central nervous system, and bones. Lymphomas can only be definitively diagnosed through a biopsy, where a piece of tumor tissue is obtained surgically and examined under a microscope. Once the diagnosis is made, many tests must be done to determine the extent of the tumor, including special X-rays, CAT scans, isotope scans, and ultrasound. Blood tests are also necessary.

Except in the case of Hodgkin's disease, where radiation therapy is highly effective for localized disease and has been the main form of treatment, it is believed that most lymphomas in young people are spread throughout the body, even though tumors may be detected in only one region. Since chemotherapy acts on cells throughout the body, it is the

most important aspect of treatment. Surgery and radiation therapy are sometimes valuable in particular circumstances. Except in Hodgkin's disease, treatment is usually given to prevent the spread of disease to the brain and spinal column.

Brain Tumors

As a group, brain tumors are the second most common cancers of childhood. They may occur at any age, including early infancy and in adolescence, but are most often seen in children 5 to 10 years old.

Symptoms include seizures, morning headaches, vomiting, irritability, behavior problems, changes in eating or sleeping habits, lethargy, or clumsiness. Diagnosis is often difficult, as these symptoms can and frequently do indicate any number of other problems, either physical or emotional. If a brain tumor is suspected, diagnostic tests usually include skull X-rays, a brain scan, and CAT scans.

Treatment depends on the type of brain tumor involved. For the most part, surgery, radiation, or both are used. Recently anticancer drugs that can be given intravenously or orally and penetrate the brain and central nervous system have been used to treat brain tumors.

Neuroblastoma

Neuroblastoma arises from very young nerve cells that, for unknown reasons, develop abnormally. More than half of these tumors occur in the adrenal glands which are located in the abdominal area near the kidneys. Neuroblastoma is found in children only, with one-fourth of those affected showing initial symptoms during the first year of life, and three-fourths before age 5.

Symptoms include a mass, listlessness, persistent diarrhea, pain in the abdomen or elsewhere. Again, these symptoms can point to other conditions. Diagnostic tests include an intravenous pyelogram (IVP), blood tests, ultrasound echo studies, and other procedures, depending upon the site of the cancer. Because most children with this particular cancer secrete a substance that can be detected in the urine, urine tests may also be performed. The diagnosis may be further established by a biopsy for examination under an electron microscope.

Surgery is performed to remove as much of the cancerous growth as possible. If some remains after surgery, radiation is frequently

used. Chemotherapy alone or combined with radiation can also be effective in treating the remaining tumor or in preventing metastases, the spread of the disease to another site.

Wilms' Tumor

Wilms' tumor is a cancer that originates in the cells of the kidney. It occurs in children from infancy to age 15, is rare in older patients, and is very different from adult kidney cancers. It may rarely be hereditary and about 5 percent of the cases involve both kidneys.

Parents frequently bring Wilms' tumor to the attention of the doctor after they have noticed a slight swelling or a lump in their child's abdomen. Symptoms such as blood in the urine, weakness, fever, loss of appetite, or abdominal pain may or may not be present.

Diagnosis begins with a physical examination and review of the child's medical history. An intravenous pyelogram (IVP) is the X-ray method most often used. A special X-ray tomogram of the kidney (nephrotomography), CAT scan, or other specialized diagnostic X-ray tests may also be ordered. Ultrasound pictures and other types of examination may be ordered as needed.

Wilms' tumor is one of several cancers for which treatments have been developed combining surgery, radiation therapy, and chemotherapy. The way in which these three methods will be used depends upon the child's medical history and general health and, above all, on the stage of the disease. Radiation therapy, for example, is not often used in children under the age of 2 when their disease is localized. Surgical treatment of Wilms' tumor (radical nephrectomy) involves removal of the diseased kidney and neighboring tissue and lymph nodes. When radiation therapy is used after surgery, its purpose is to guard against recurrence of the cancer where the tumor has been removed. Chemotherapy is used to treat virtually all cases of Wilms' tumor.

Retinoblastoma

Retinoblastoma is a relatively rare cancer of the eye. It may be hereditary, and one-third of the cases involve both eyes. Retinoblastoma can be seen by looking at the young person's eye, but is usually diagnosed by an examination under general anesthesia using an ophthalmoscope, an instrument used in examining the interior of the eye. The disease tends to remain localized for long periods but in advanced stages can

metastasize, or spread to other parts of the body. X-rays, bone marrow examination, spinal fluid examination, and a bone scan can be done to check for metastases.

If diagnosed early, it is possible to destroy the tumor with radiation therapy and preserve normal vision. If the tumor is so large that there is no hope of maintaining useful vision through radiation, the eye is removed. In cases where both eyes are involved, an attempt is made to preserve vision in both eyes through treating with radiation. When advanced disease is found in both eyes, an attempt is made to preserve vision in *at least* one eye. If there is any possibility of useful vision, all efforts are made to preserve it. Chemotherapy, radiation, or both may also be used to treat metastases.

Rhabdomyosarcoma

Rhabdomyosarcoma, also called rhabdosarcoma, is a type of soft tissue sarcoma arising from muscle cells. It occurs slightly more frequently in males and usually affects children between the ages of 2 and 6. Although it can occur in any muscle tissue, it is generally found in the head and neck area, the pelvis, or in the extremities.

Although rhabdomyosarcoma tends to grow and spread very rapidly, fortunately its symptoms are quite obvious compared to those of other forms of childhood cancer. A noticeable lump or swelling is present in almost all cases. Other symptoms depend on the location: if the growth is near the eyes, for example, a vision problem may develop. If the neck is involved, there may be hoarseness or difficulty in swallowing. Definite diagnosis relies on biopsy. Evidence of tumor spread is sought with X-rays, tomograms, gallium scan, bone scan, liver scan, and bone marrow examination. Other procedures, such as lymphangiography, brain scan, and spinal fluid examination, may also be done, depending on the tumor's location.

Traditionally, surgery has been the primary treatment, followed by intensive chemotherapy and radiation. However, if the tumor is so large that surgery presents a major risk to the patient or would result in serious disfigurement or physical impairment, then chemotherapy, radiation, or both are used to reduce the tumor's size until it can be more safely removed. In some cases, the cancer can be treated effectively with chemotherapy and radiation alone.

Osteogenic Sarcoma

Osteogenic sarcoma, also called osteosarcoma, is the most common type of bone cancer in children. It arises in the ends of the bones. The bones most frequently involved are the large bones of the upper arm (humerus) and the leg (femur and tibia). Osteogenic sarcoma usually occurs between the ages of 10 and 25, and is more common among males than females.

Young people with this type of cancer generally complain of pain and swelling which they sometimes blame on an injury. Diagnosis can be difficult, as the disease is easily confused with local infection, effects of injury, glandular deficiencies, arthritis, vitamin deficiencies, and benign tumors. Although osteogenic sarcoma may be suspected by the way the bone looks on X-rays, diagnosis can be confirmed only by biopsy. Since the disease commonly spreads (metastasizes) to other parts of the body, especially the lungs, chest X-rays, lung tomograms, CAT scans of the chest, and an X-ray skeletal survey or bone scan may also be done before treatment.

Treatment usually involves amputation of the affected limb, followed by a course of chemotherapy using one or more anticancer drugs. A prosthesis (artificial limb) and physical rehabilitation are important parts of therapy.

The use of implants and limb preservation as opposed to amputation is still experimental. In this process, the portion of the bone that is cancerous is removed and replaced with a special implant. For more information on this technique and whether its use is appropriate for your child, ask your physician.

Ewing's Sarcoma

Ewing's sarcoma differs from osteosarcoma in that it affects a different part of the bone—the bone shaft—and tends to be found in bones other than the long bones of the arm and leg, such as the ribs. Like osteogenic sarcoma, it usually occurs between the ages of 10 and 25, is seen more often in males, and frequently spreads to other bones and the lungs.

Young people with this type of cancer usually have more general signs—fever, chills, and weakness—than are present in osteogenic sarcoma. Because the symptoms can point to other conditions, definitive diagnosis depends on biopsy. A bone survey, bone scans, chest X-rays, lung tomograms, liver scans, and brain scans may be done as well to look for evidence of metastases.

Treatment involves use of a combination of intensive radiation therapy and chemotherapy.

Treatment

When a diagnosis of cancer is confirmed, it is best for your child to begin treatment at a treatment center that has an experienced staff and the resources to apply the most effective form(s) of treatment right from the beginning. Your family physician or pediatrician can help you find such a center where specialists in the area of childhood cancer will be in charge of your child's care.

Your child's treatment will be based on medical advances learned from treating many other young people. For some types of cancer, treatment programs may be well established. However, research for effective treatments is constantly underway, and your child may be treated under a research protocol (or regimen), which is a general treatment plan that several hospitals use for treatment of one type of cancer. The protocol is carefully designed to establish the ideal

type, frequency, and duration of treatment.

Still, because children's reactions to therapy vary, the treatments may need to be modified to allow for individual differences. If a child is unable to tolerate a treatment plan or protocol, and minor adjustments do not correct this, another treatment plan may be begun or a specially designed program created. Before any therapy begins, the doctor should discuss the treatment program with you, including benefits and risks, and obtain your consent before treatment begins. Depending on the hospital's policy on the age at which a patient's agreement is necessary to undertake therapy, your child may also be required to approve it.

The treatment plan may look complicated at first, but each of the steps will be carefully explained and you will soon become familiar with the routine.

At the treatment center, your child may be seen by different physicians from time to time, all of whom will follow the basic treatment plan. Your child may also be examined by resident physicians, fellows, and medical students who are working in the center as part of the educational program in cancer medicine and pediatrics. All residents and fellows are experienced physicians who are near the end of their training period, and their work is supervised by a senior physician.

In addition to these physicians at the treatment center, your family physician or pediatrician may continue to play an active role in the care of your child. With current information on the therapy prescribed for your child, he can remain a source of advice and treatment for routine medical care and problems. Especially if distance between your home and the treatment center is a factor, your local physician may be called on to do blood tests or administer chemotherapy prescribed by the center physicians, thus reducing the number of visits to the center. If that is the case, your child's initial hospitalization or outpatient treatment will usually take place at the center and you will return there for periodic checkups.

The exact type of treatment your child will receive depends on the type of cancer he has. Most patients receive surgery, radiation therapy, chemotherapy, or a combination of these. These treatments aim at bringing about a remission, the decrease or disappearance of symptoms of the cancer. There are two major phases of treatment: remission induction and remission maintenance. Remission induction attempts to establish a "clinical" remission,

when detectable cancer has been eliminated. If this phase is successful, maintenance therapy aims at reaching undetectable cancer cells which experience has shown may remain in the body. Remission induction may be accomplished through surgery, radiation, or chemotherapy. Maintenance therapy involves the use of chemotherapy and may last only a few months or go on for several years.

Hospitalization

With admission to the hospital, the child enters a new world, with new people and strange machines, procedures, and routines. He sees other patients and observes their conditions. He strives to achieve some kind of order out of the confusion that surrounds him. From the beginning, it is important to encourage your child to ask any and all questions, express all concerns, and seek answers to what he does not understand in his hospital environment.

Hospitalization can be a traumatic experience for any child. This is especially true when he is removed from his parents, on whom he depends for emotional

and social support. More and more hospitals have unrestricted visiting hours for parents. Beds in the child's room or bedrooms adjacent to the area are sometimes made available to parents so they can be with their children during extended hospital stays. If that is not the case in your hospital, you might want to ask if you can sleep in a chair near the child's bed during crucial times, like the days before and after surgery, or the first night in the hospital.

Experiencing difficult medical procedures and continually meeting new people who do all sorts of things to him builds up tension. The child may become nervous, anxious, and unruly. For the hospitalized child, some form of outlet in play is essential.

Most hospitals have playrooms for patients. These offer children an opportunity to interact with one another in a way similar to their play with friends at home. In hospital playrooms, children may relax and become less fearful and better able to cope with their feelings about hospital equipment, medical procedures, and medical personnel. They may act out their concerns in play and thus deal with them in their own way.

Playroom personnel are often trained professionals with backgrounds in psychology, special education, childhood development, social work, nursing, or recreational therapy. As part of the

treatment team, they are in a position to alert other caregivers and parents about concerns the child may be able to express only through play.

If the child is confined to bed and unable to go to the playroom, recreational therapists or child-life workers may pay bedside visits.

Playrooms may also be equipped to provide outlets for the energies of older children and adolescents who may enjoy taking part in crafts or playing games appropriate to their ages. Record and tape players for use in the playroom or loan for their own rooms are popular with teens.

Hospitalization threatens the growing sense of independence in older children. The young person is taken to the doctor, taken to the hospital, given treatment. His role is passive rather than active. The lack of independence resulting from hospitalization and cancer treatment is particularly displeasing to the adolescent, who may frequently and loudly protest his forced dependence. It is not uncommon for adolescents to refuse treatment, break hospital rules, miss outpatient appointments, or undertake activities against doctor's orders. Besides rebelling against the feelings of dependency, teenagers may be acting on the normal adolescent resistance to authority figures and reluctance to appear different from peers outside the hospital. Some hospitals have responded by relaxing certain rules so teenagers can dress in street clothes whenever possible, and have visits from their friends. Hospitals may also fill the oncology ward's refrigerator with their favorite foods. Parents can help by allowing the adolescent a share of the responsibility for his own care and by respecting his need for independence and privacy, hard as that may be under the circumstances. But more than anything else, your teenager needs to know that you are there if he needs you and that he can rely on you for honest, dependable answers.

Surgery

For many solid tumors, surgery is the primary and most effective treatment. For very large tumors, radiation or chemotherapy is often used before surgery to reduce the size of the tumor, make surgery safer for the patient, and lessen any physical or functional defects.

The young person facing surgery is likely to be afraid. To counter some of that fear, many hospitals prepare patients for surgery by letting them visit the operating and recovery rooms, where they can meet and talk with the people who will be present during the operation. These people ex-

plain what they will be doing and how they will look. They might, for instance, bring along a surgical mask and put it on for the younger child. This advance preparation can at least ease the shock and accompanying fear of the sterile operating room, strange equipment, and uniformed, masked personnel.

In addition, the patients should be encouraged to discuss their feelings and fears concerning surgery. Young people commonly worry about the anesthesia, whether there will be a lot of pain, how their bodies will be changed, and whether their parents will be there when they wake up. If an internal organ has been removed, some children feel a lack of wholeness afterwards. Amputations for bone cancer, primarily osteosarcoma, may produce similar feelings. Amputation also means the young person must accept and learn to use an artificial limb (prosthesis).

Your child will have questions about his surgery, and these must be answered as honestly as possible, since he may feel betrayed if what you told him does not match up with what actually happened. You will want to learn as much about the operation as possible. The surgeon and other members of the treatment team can help you. If you wish, they may be able to arrange for your child to see and talk with another young person who has had the same type of surgery and is doing well. If a limb must be removed, center staff might show the child a prosthesis. If appropriate, your child may begin to practice walking with crutches even before amputation of his leg makes crutches temporarily necessary.

Chemotherapy

Chemotherapy is treatment with anticancer drugs. These drugs may be taken by mouth (pills or liquids), or given by injection into a muscle (intramuscular or IM), a vein (intravenous or IV), or just below the skin (subcutaneously or SQ). These are different ways of getting the medication into the bloodstream so that it can be distributed throughout the body. Another method, used for treatment of brain tumors and prevention of central nervous system disease in leukemia, is to inject the antican-

cer drug into the spinal fluid (intrathecal or IT).

Insertion of the IV needle may be painful and, once in the vein, the drugs may cause an uncomfortable burning sensation. If the drug leaks from the vein, it may severely burn the skin, so care must be taken to make sure the IV is securely in place, and the nurse or doctor must act immediately if the needle comes out of the vein.

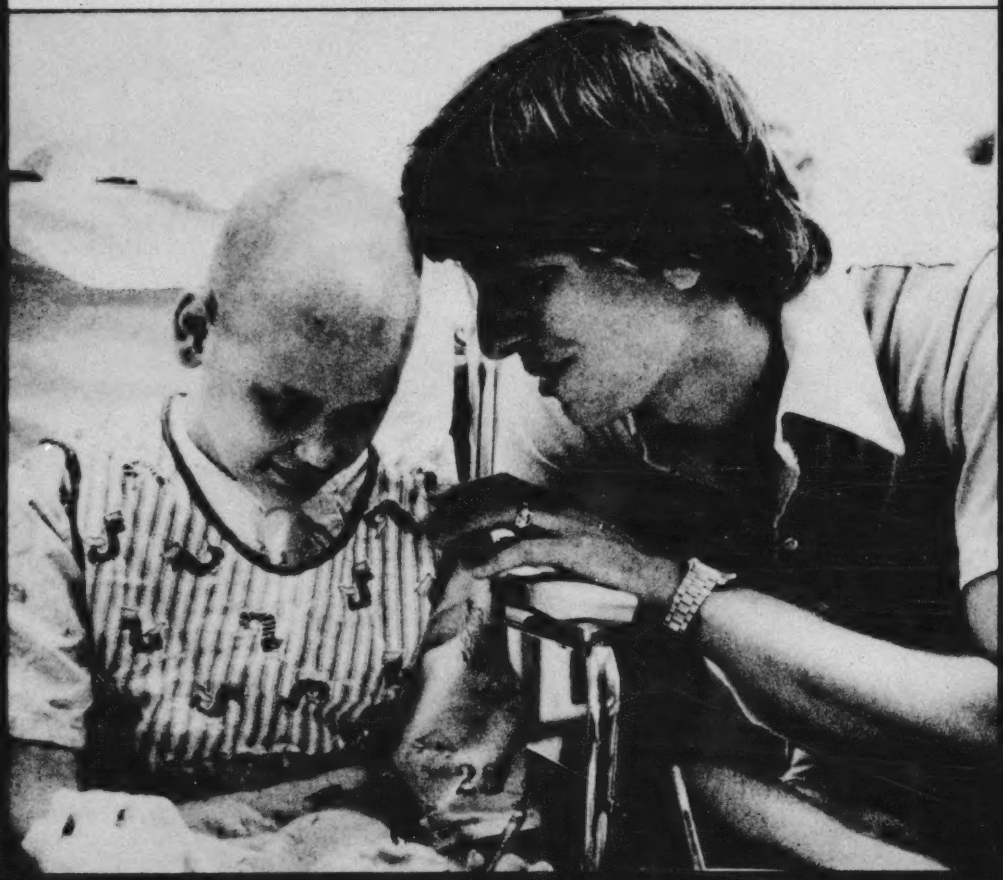
Injections are generally given by physicians or nurses, but pills may be given at home. Taking chemotherapy pills can sometimes be a problem with younger children, but the tablets can be broken into smaller pieces for swallowing, or powdered and mixed with apple sauce, jam, custard, etc. Older children, particularly adolescents, may wish to be responsible for taking and keeping track of their oral medication(s). However, it is still important for parents to be familiar with the medications and check to be sure they are being taken correctly.

Whether you or your child is responsible, you may want to develop a system for keeping track of when medications are taken. Marking a special calendar when medications are taken is one way of doing this.

Chemotherapy and its Side Effects

Once in the bloodstream, chemotherapeutic drugs are taken up by cells that divide rapidly, such as cancer cells. In the cancer cell the drugs act by interfering with the duplication and growth of the cell, primarily by preventing it from dividing or depriving it of a substance it requires to function, and the cell is eventually destroyed. Anticancer drugs can affect not only cancer cells, but also other rapidly dividing normal cells such as those in the gastrointestinal tract, bone marrow, hair follicles, and reproductive system. Because of this, unwanted side effects of the treatment can and often do occur in normal tissues. Almost all side effects, however, are temporary.

One common side effect of chemotherapy is the reduction of the bone marrow's ability to produce the normal amount of blood cells. This may put your child at greater risk for anemia (if significantly fewer red blood cells are being produced), bleeding (if production of platelets is down), or infection (if his white cell count,



particularly that of the neutrophils, is low). No medications or special diets are known to reverse chemotherapy's effect on the bone marrow and the resulting lowering of blood counts. Your physician will let you know if the blood counts are so low that special precautions must be taken. In general, you should be particularly alert to any signs of infection, bruising, or bleeding and notify your physician should they occur. Anticancer drugs, their routes of administration, physical descriptions, and side effects are listed in the foldout chart starting on page 93.

Many side effects from anticancer drugs are possible, and the following points are good to keep in mind:

1. Most side effects can be lessened by taking appropriate measures before, during, and after chemotherapy. (See the following section for how to control side effects.)

2. Side effects vary in severity and type from person to person and treatment to treatment. Your child will not necessarily have the same reactions as another child, but it is important for you to be aware of those problems that occur commonly so you may recognize their occurrence early.

3. Most side effects are reversible, and will improve after stopping the drug. Some, such as hair loss and bone marrow depression, may lessen or disappear even without discontinuing chemotherapy.

4. Slightly decreasing the drug dosage because of serious, persistent, and unreasonable side effects usually will not decrease a drug's ability to be effective. Consequently, even if your child's dose is reduced in an effort to lessen or eliminate these side effects, his chance of recovery will not be changed.

5. Side effects of chemotherapy may be classified as common or uncommon and as acute (immediate) or delayed (days to weeks after chemotherapy):

Common acute side effects:

- Nausea and vomiting
- Pain and burning at injection site

Less common acute side effects:

- Allergic reactions (hives; rash; swelling of eyelids, hands, and feet; shortness of breath)
- Drug extravasation (leaking of drug out of vein into skin)

Common delayed side effects:

- Hair loss
- Mouth soreness and ulcers
- Constipation (especially with Vincristine)
- Bone marrow depression (low blood counts)

Uncommon delayed side effects:

- **Jaundice (yellow tint to skin and eyes due to liver problems)**
- **Hemorrhagic cystitis (bloody urine due to bladder irritation—especially with Cytoxan)**
- **Mental or nervous system changes (lethargy, tiredness, lack of coordination)**

Each drug has the potential of producing its own side effects. Your doctor can tell you which ones your child is most likely to experience.

6. Daunorubicin or its chemical cousin Adriamycin may cause heart damage if the cumulative dose over time exceeds certain levels. Your physician should keep a careful record of the cumulative dose and should warn you if your child passes the usual limits.

7. Recent research has raised the possibility of long-term effects of treatment on such areas as reproductive and intellectual abilities. Your child's physician can tell you more about these in relation to his specific care and treatment.

Controlling the Side Effects from Chemotherapy

Certain side effects, while not dangerous, are bothersome and you can try to avoid or control some of these through specific measures:

1. Constipation from Vincristine: Encourage increased consumption of fluids and roughage (juices, fruits, vegetables, bran cereals) starting the day before injection and continuing for a week. If the child does not have a bowel movement for a considerably longer period of time than is usual, contact your physician. If constipation is a common problem, the regular use of a stool softener may be necessary while the child is on Vincristine.

2. Pain: Aspirin should not be used for pain or fever since it can affect blood clotting and upset the stomach. Acetaminophen (aspirin-free pain reliever) is usually used instead. If pain is severe or persistent, contact your physician. If the child has a fever as well as pain contact your physician before giving any medication for pain.

3. Tissue burns from Vincristine, Daunomycin, or Adriamycin leaking at the site of injection: Any swelling,

redness, or pain occurring during an injection or up to a few days afterwards should immediately be brought to the attention of the doctor or nurse. Prompt treatment may be necessary to prevent a severe burn and ulceration of the skin.

4. Heartburn and stomach ache from Prednisone and Dexamethasone: To prevent this, give one-half glass of milk or one or two tablespoons of an antacid with each dose.

5. Hair loss from Vincristine, Adriamycin, Methotrexate, Cytoxan, etc: This will occur in varying degrees in each child, depending upon which drugs and which schedule of drugs they receive. There is no way to prevent hair loss, short of discontinuing medication. Experimental attempts to prevent hair loss, such as wearing a special headband or ice cap during drug administration, are being undertaken, but their results are inconclusive. Since beneficial effects of chemotherapy are necessary, hair loss is considered an "acceptable" side effect. The hair will grow back, but adequate regrowth takes months. In the interim emotional stress exists, especially in teenagers. If marked hair loss appears to be occurring, your child may want to begin considering a wig. Caps or scarves may also be worn. The wearing of a wig will *not* hamper hair regrowth.

6. Mild to severe mouth soreness is caused occasionally by several drugs (e.g., Methotrexate, Adriamycin). Good oral hygiene is important during this period. Many people use special mouthrinses to ease the discomfort. (See the discussion of mouth care in "Common Health Issues" for more information.) No particular regimens are known to regularly prevent mouth soreness from occurring.

7. Nausea and vomiting, also caused by several drugs, can often be relieved and sometimes prevented by certain medications. Unfortunately, no perfect drug exists to prevent nausea and vomiting. Those that are effective are most helpful if given before chemotherapy. If these symptoms are marked, ask your physician about prescribing medication to counteract them. Hypnosis and relaxation exercises are used in some treatment centers to alleviate these symptoms.

8. Hemorrhagic cystitis (irritation and bleeding from the bladder) from Cytoxan: The likelihood of this occasional side effect may be reduced by see-

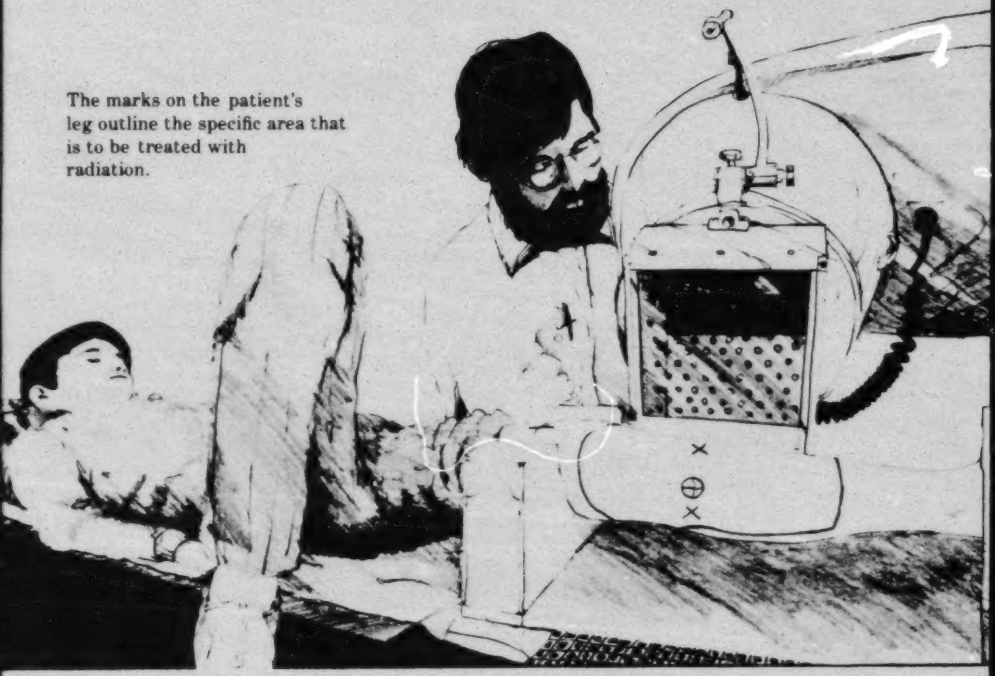
ing that the drug does not rest in the bladder for a long time. This is best done by giving the drug early in the day and seeing that urination is increased by encouraging your child to drink plenty of fluids throughout the day (thirst cannot be relied on). This will assure elimination of the drug from the bladder. The amount of liquids to be given depends on the child's size, so discuss this with your physician. This complication may occur shortly after the drug is given or show up weeks or months after the patient receives Cytoxan, so pink or bloody urine occurring at any time after therapy should be immediately reported to the doctor.

9. Some drugs increase sensitivity to the sun, so a complete sun-blocking lotion containing PABA (check the product's list of ingredients) should be used to prevent burning.

Finally, it is helpful to discuss with your physician any of the listed side effects and any other changes in your child which you observe.

Radiation Therapy

Radiation therapy is treatment by high energy X-rays. The basic principles of radiation therapy are simple: X-rays, radium, and other



The marks on the patient's leg outline the specific area that is to be treated with radiation.

sources of ionizing radiation are used to destroy cancer cells. The interaction between the radiation rays and the cellular tissue damages the DNA within cells (the genetic code that directs development), causing the cells to die as they are about to divide. The doses used kill the cancer cells but have a minimal effect on the surrounding normal tissues. The result is a reduction of the tumor's size.

Radiation may be used alone, or in combination with surgery or chemotherapy, or both. There is no pain or discomfort during the treatment. It is much like having an ordinary X-ray taken, except that the child needs to hold still for a few minutes longer. In some cases, young children need to be sedated in order to hold still for the radiation treatment. You will not be allowed in the room during treatment, as this would expose you to needless X-rays. Younger children may find it frightening to be left alone in the room during radiation therapy. If you accompany your child to treatment, it may be reassuring to let him know that you are just outside the room. In some hospitals closed circuit television or viewing windows allow you to watch your child receive treatment, and in these cases the child may feel easier knowing that you can see him all the while he is being treated. Most radiation departments are willing to give you and your child a tour of the treatment area before the first treatment. During this time the technologist will explain the machines. A trip to the radiation therapy room ahead of time may also help quiet fears about the equipment, especially its imposing size.

Before starting therapy, a physician specializing in radiation therapy will talk with you and explain the details of the treatment. He will also use dye to mark the area to be irradiated. Once in place, this dye should not be washed off for the duration of the treatments as it will be used as a guide for aiming the radiation. While radiation therapy is being received, soap or lotion should not be used on these lines or within the radiation field, where the skin will become tender. The area should also be kept dry.

Areas of the body not being treated are often protected from radiation by special shields made of lead.

Side Effects of Radiation Therapy and Controlling Them

Your child will not be radioactive after or during radiation therapy. Neither you nor anyone

else need fear contact with him. Among the real side effects of treatment, which vary according to the site receiving the radiation, are:

1. Skin damage. The skin in the treated area may be somewhat sensitive, and therefore should be protected against exposure to sunlight and irritation. During treatment, it should not be exposed to sunlight. After treatment is completed, the skin will still be sensitive, and a sun-blocking lotion containing PABA should be used to prevent burning. If the head is affected, soft hats and scarves are comfortable and fashionable. Your physician may also prescribe baby powder or corn starch, an antibiotic ointment, or steroid cream to relieve itching and pain and to speed healing. Nothing, however, should be applied to the treatment area without the recommendation of the person in charge of the treatment.

2. Sore mouth (if the head and neck are within the irradiated area).

Your physician may prescribe a mouthrinse, and the hints on mouth care provided in "Common Health Issues" will also help.

3. Hair loss. Hair is frequently lost from the area receiving the radiation therapy. This loss is usually temporary, with hair growth beginning about 3 months after the completion of treatment. Initial adjustment to even temporary hair loss can be difficult, but after a time children are able to play, work, and go to school without undue embarrassment. Some will want to wear a wig, cap, or scarf.

4. Nausea, vomiting, and headaches. A few children have these symptoms following radiation therapy to specific sites, such as the head or abdomen. These problems may last for about 4 or 5 hours, and can be relieved by medicines prescribed by your doctor. In terms of diet, small, frequent meals are recommended. You may want to see that your child eats 3 to 4 hours before treatment.

5. Diarrhea after radiation to the abdomen (or pelvic area).

This condition usually responds to simple measures such as nonprescription drugs or medications prescribed by your doctor. A low residue diet avoiding fresh fruits, vegetables, and fried foods may also help. Occasionally, treatment will have to be suspended until the symptoms subside.

6. Late effects. Following irradiation to the brain and/or central nervous system, some children seem to be drowsy and need more sleep. This symptom may begin at various times, even as late as 5 to 7 weeks after therapy has been completed. It usually lasts about 5 to 10 days. Several days before the drowsiness occurs, the child may lose his appetite, have fever or headache, nausea and vomiting, and be irritable in general. This is a temporary condition; nevertheless, *it is important to report such symptoms to your physician.* Other post-therapy symptoms your doctor will want to evaluate are dizziness, sight disturbances, increased appetite, stiff neck. None of these may occur, but if they do, you should contact the physician.

7. Long-term effects. Recent research suggests that radiation therapy to the head may affect intelligence and/or coordination, depending on several factors, including the age of the child at the time of exposure. Research also points to the increased possibility of developing a second tumor in an area treated with radiation. A second tumor usually develops several years after the exposure. Your child's physician or radiation therapist can tell you more about these long-term effects in relation to your child and his treatment.

New Treatments

The search for new and more effective drugs to treat cancer is a continuing one. Each year, thousands of drugs are tested in experimental animals for activity against cancer. The most promising of these are further studied to determine whether they might be safe and effective for human use and to establish the proper dosage.

Newspaper and magazine reports of such research can be unintentionally misleading. A so-called new drug "cure" may refer to an agent that is effective against animal leukemia and has not yet been tested in patients. Or it may be a drug with limited usefulness in one particular type of cancer or in cancer at one particular stage. If you have any questions, discuss such reports with your child's physician, who is in the best position to evaluate them.

Some parents are concerned that if a cure for cancer is found in one hospital, it will not be known in another. Actually, the medical world is relatively small,

and in this age of rapid communications, the discovery of a successful new treatment method will become generally known almost immediately.

Unproven Treatments

Unusual remedies and approaches to cancer treatment often achieve public notoriety. As the parent of a child with cancer, it is inevitable that you will hear of these yourself or have them brought to your attention by others. Patients, particularly older ones, may also hear of such treatments.

These treatments may involve unusual forms of therapy or strict dietary regimens that are reported to cure cancer. As a group, these treatment techniques are often called "unproven" methods, because they have not been tested in the same strict method as have treatments employed by your physician. Reports of cures seldom provide enough information to compare their effectiveness with that of more conventional therapies.

The guarantee of cure these treatments offer may seem attractive when judged against the difficult treatment course of conventional therapies, and the fact that your physician cannot absolutely predict the results of that treatment. If you develop an interest in an unconventional treatment or have any questions, discuss it with your physician, who should be able to provide or direct you to relevant information. The treatment team's primary concern is that your child receives the most effective treatment possible. If some magical, easy cure for cancer existed, caregivers would be the first to make it available.

Because many people have heard of unproven methods of cancer treatment, you, or occasionally the older patient, may find yourself in the position of defending your decision to follow conventional treatment methods. This can be a frustrating situation and place a burden on you during an already stressful time. It is important to remember that suggestions are usually well-intentioned, and that they come from those who are not well informed about treatment advances. The best way to deal with this may be to provide these people with more information and make it clear that you appreciate their interest but that you feel your child is already receiving the best treatment available.

Common Health Issues

A number of routine health-related matters are common to all young people with cancer. Some of these are discussed below and should provide you with general information on some issues of concern to you. You may want to check with your physician or others in the treatment center to see how these general statements apply to your child's specific situation.

Infections

Because of lowered white blood cell counts from chemotherapy, infections can be particularly serious in a child with cancer who is receiving chemotherapy. Your child may handle most infections as well as other children. Still, there is the potential for the development of serious and unusual infections, and any sign of infection, such as a fever, should be reported to your child's physician as soon as possible.

To determine the cause of the infection, the physician may ask that cultures be taken of any sores as well as of the blood, urine, throat, and stool. If it is a bacterial infection, antibiotics will be given to control it. These may be given either orally or intravenously. Depending on the severity of the infection and your physician's policy, your child may be hospitalized. The cultures taken earlier will usually be repeated to check the course of the infection and the effectiveness of the antibiotic treatment.

Antibiotics will not be used if the infection is caused by a virus, since antibiotics are ineffective in treating viral infections. In these cases, chemotherapy may be stopped for a time and medication given to ease the symptoms while your child's blood counts and general condition are closely monitored.

Some viral infections, such as chicken pox, can be particularly dangerous to a child receiving chemotherapy, since complications from the infection may arise. Notify your child's physician immediately if your child has been exposed, since certain measures can be taken, such as decreasing drug doses or use of a special gamma globulin. If your child attends school, teachers should know to inform you at once if a schoolmate develops chicken pox.

Once a child has had chicken pox, most are immune for life and will not contract it even if exposed while in relapse or on chemotherapy. However, some children on chemotherapy who have already had chicken pox may, when exposed to it again, develop shingles. This is a blistery-like skin rash that resembles chicken pox but, instead of appearing all over the body, is confined to one area. Although complications from shingles are less likely than from chicken pox, notify your physician if you suspect your child has shingles.

Regular or red measles (also known as Rubeola or hard 9-day measles) may also be more serious for a child on chemotherapy. If the child is exposed to this type of measles, his physician should be notified. Regular gamma globulin may be given in an attempt to prevent or control the infection.

There is no evidence that infections play any role in activating the cancer or causing a relapse. As stated earlier, your child will tolerate most infections as well as if he did not have cancer. Chemotherapy may be stopped during the period of infection, depending on the severity of the infection and the child's white cell count. Your physician will be the best

judge of whether this should be done.

Your child may miss some of his oral medications due to a gastrointestinal infection. Contact the physician or treatment center if this occurs. Brief interruptions of medicine for such reasons do not seem to jeopardize the welfare of the child.

Activities

Cancer and its management may seem to consume an overwhelming amount of your time. For the child, however, the best antidote to this unwelcome (and at times painful) attention is to encourage him to live as normal and active a life as possible. Check with your physician to see if any special precautions should be taken.

If your child feels well, there is no need to insist on extra rest. However, there may be days, especially after chemotherapy or radiation therapy, when he may seem lethargic or appear to need more rest. This is a normal result of the treatment. Other days his normal level of energy will return, and you should encourage him to get regular rest and pursue normal activities.

In complete remission, there are usually no restrictions on activity.

Diet

Good nutrition is an important part of your child's treatment. In general, your child's normal diet should be continued during his cancer treatment unless your physician gives you a special one. A few diet hints are listed below:

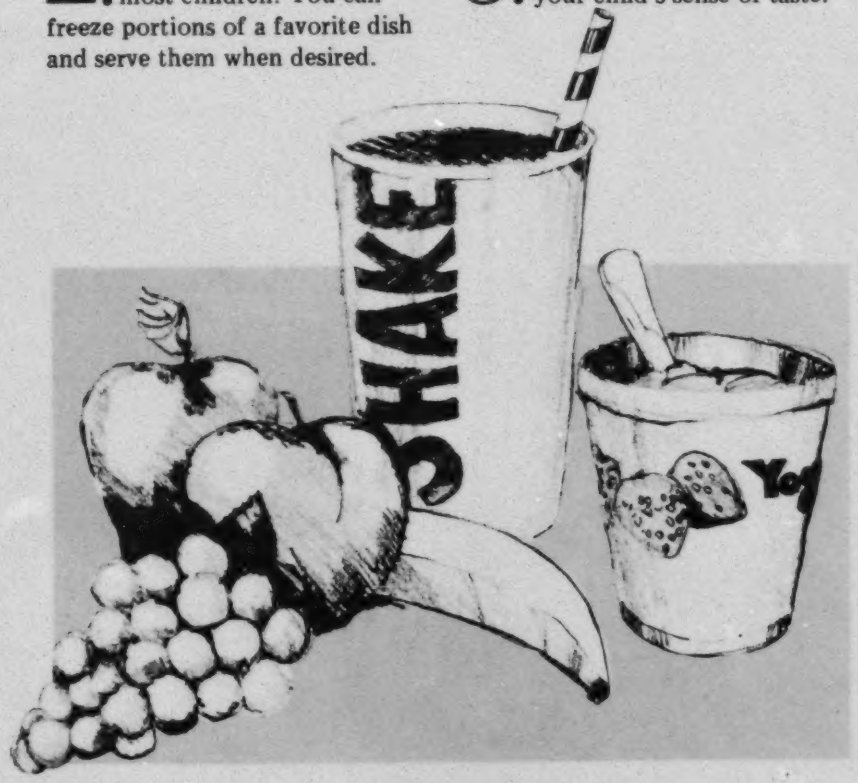
1. Build meals around your child's favorite foods. Variety is not as important as intake.

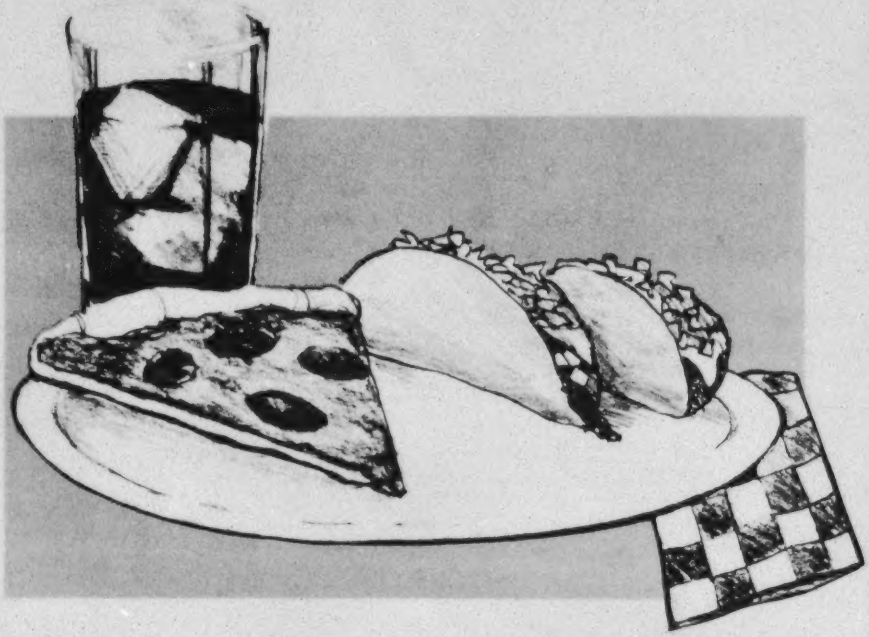
2. Small, frequent meals and snacks are attractive to most children. You can freeze portions of a favorite dish and serve them when desired.

3. Smaller bites and frequent sips of water, milk, or other unsweetened drinks will make chewing and swallowing easier.

4. Avoid empty calorie foods. Such items, e.g., soft drinks, chips, candy, reduce your child's appetite without giving him nutrients. By contrast, milkshakes (with eggs or yogurt in them), yogurt, fruit, juices, or instant breakfasts provide extra calories and protein.

5. Some types of chemotherapy may temporarily alter your child's sense of taste.





Well-seasoned foods such as spaghetti, tacos, and pizza may seem especially good at times.

Sometimes adding extra salt or sugar, or using less, may make foods taste better. However, because of fluid retention, patients on cortisone drugs should limit salt in their diets.

6. A decrease in appetite is common to some types of chemotherapy. (See the drug chart for examples.) But this must be countered with an *increase* in fluid intake beginning a few days before the chemotherapy and continuing for a few days after it.

7. If appetite is poor, the addition of a single multivitamin (one without *folic acid*, if your child is taking Methotrexate) per day may be advisable. Be sure to ask your doctor before beginning vitamin supplements.

8. If your child is taking oral medication at home, the time of day that medication is given may be critical. Some are best given in the morning, some at midday, some on a full stomach, etc. Be sure to ask your doctor when and how medications should be administered.

(See the list of additional materials beginning on page 79 for more information on diet and nutrition for young people with cancer.)

Immunizations

Live virus vaccines (regular measles, German measles or rubella, mumps, polio) should not be given. They may be dangerous to a young person who is under medication that suppresses the normal response to these vaccines. Diphtheria, whooping cough, and Tetanus immunizations (DPT or DT shots) are not "live" and are considered by some to be safe for those being treated for cancer. Ask your physician before allowing any immunizations to be given. If your child has never received the regular measles vaccine, report this to the physician.

Other Medications

A young person under treatment should not take any other medications without the physician's approval. It is important to note that some medications ordinarily used to treat common conditions should be avoided. For instance, when the child's platelet count is low, avoid aspirin and glyceryl guaiacolate (present in certain cough syrups). If he is on Prednisone or Dexamethasone, avoid aspirin, as it may stimulate bleeding. If fever, pain, or aches are present, acetaminophen (aspirin-free pain reliever) may be used, but the presence of the condition (fever, pain, etc.) should be reported to the physician.

Mouth Care

It is especially important to keep the young person's teeth, mouth, and gums clean in order to protect him from tooth decay and infection. Also, if a child with a poor appetite receives mouth care before meals he may feel better about eating.

Teeth should be brushed after each meal, using a soft toothbrush. After each use, the brush should be rinsed well with cold water, shaken thoroughly, and hung to dry on the toothbrush rack. Disposable paper cups should be used for rinsing out the mouth. Dental floss may be used, if care is taken not to cut the gums.

To prevent the severe tooth decay that can result when saliva flow is reduced from radiation to the head and neck, older children should use a fluoride mouthrinse as often as recommended by the physician or dentist. Fluoride gels may be prescribed for home use.

Children whose treatment has not included radiation to the head

and neck should also use a mouthrinse frequently during the day. One suggested mouthrinse is a mixture of salt and baking soda (one-quarter teaspoon of each in a cup of water).

Infants and toddlers can be given mouth care by wrapping a soft cloth around your finger and gently wiping the teeth and gums with a solution of mouthrinse.

When the young person has low blood counts, mouth care should be especially gentle. *Very soft* bristle tooth brushes should be used. If you prefer a Toothette (a spongy swab), discard it after use. Your child should *not* use water jet devices or dental floss when his counts are low and he is prone to infection. Watch for sore areas, or red and white patches. Alert the physician to any red or white patches, mouth sores, or irritated areas that develop in the mouth.

When mouth sores, bleeding areas, or irritated areas are present, only the mouthrinse described above or one prescribed by your doctor is appropriate. Moreover, they should be used at least every 2 to 3 hours. Your child should rinse his mouth out well after every meal and before bedtimes. Also, Q-tips or glycerin swabs can help remove food particles.

If mouth sores become painful, a local anesthetic ordered by your physician may help and can be applied as often as recommended. When your child has mouth sores it may be easier to eat if you apply an anesthetic directly to sore gums or to other *small* areas in the mouth immediately before meals. If used as a rinse or applied to the back of the throat, however, give it to your child at least 1 hour before meals. Otherwise, the normal gag-reflex may be suppressed and there could be a danger of choking.

If your child has dry lips, petroleum jelly or a lip pomade can prevent cracking.

Dental Care

Ideally, your child should have a thorough oral examination and any necessary dental work before cancer treatment begins. This is not always possible. Although dental work may have to be delayed because of the cancer and side effects of treatment, it should not be neglected.

When blood counts are normal, dental work is an important part of overall health care. But you should check with the physician before scheduling dental work. Even checkups should be avoided during times when the blood count is low.

Bleeding

A low platelet count may predispose your child to bleeding. In that case, special precautions should be taken to curtail his "contact" activities. For the older child, it is wise to limit activities such as football, soccer, skateboarding, or rollerskating.

To control episodes of sustained bleeding, remember the following:

- Apply pressure until the bleeding stops—a clean towel, handkerchief, or cloth *firmly* applied to the wound will slow or stop the bleeding.
- For nosebleeds, have the child sit up. Don't let him lie down. Pinch the bridge of the nose over the bone for 10 minutes. The pressure must be tight on both sides to be effective.
- Notify the doctor promptly if bleeding continues.

Transfusions

If necessary, transfusions of whole blood or specific components of blood can be given to cancer patients. Blood transfusions may be given to control the anemia that may result from a low red blood cell count. The blood may be given as whole blood, which includes the plasma or liquid portion of the blood, or as "packed cells," a transfusion of blood from which the liquid portion has been removed.

Platelet transfusions may be given if the patient has a low platelet count because of the disease or its treatment and is at increased risk for bleeding. Platelet transfusions are most commonly given if the patient is bleeding or is in a situation that will predispose him to bleeding, such as preparing for surgery.

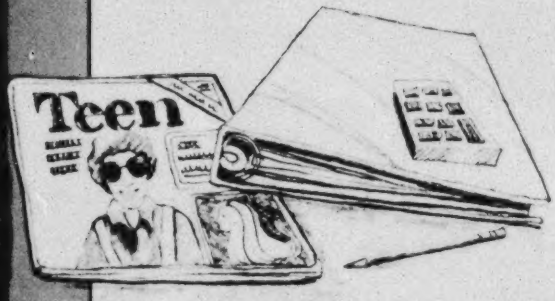
Since each individual has a characteristic blood type, tests are run to be sure the donor's blood is compatible with the recipient's. This process is called blood typing and cross matching.

In transfusions of white blood cells, the need for compatible tissue type between donor and recipient is greater, and siblings and parents of the patients often serve as donors. In the process of collecting white cells for transfusion to the patient, the other components of the blood are returned to the donor. White cell transfusions may be given to a patient with a low white count and a serious infection that is not responding to treatment.

Tips for Clinic Visits and Medical Procedures

Listed below are some ideas for making treatment and medical procedures easier. These are based on the experience of other parents and are offered only as suggestions.

1 Bring a favorite toy or book to the clinic to comfort your child during the wait and the discomfort of treatment. Since waits are sometimes long and space is limited, reading, crafts, or quiet games can help pass the time. Teenagers may want to bring crafts, electronic games, playing cards, books, or magazines.



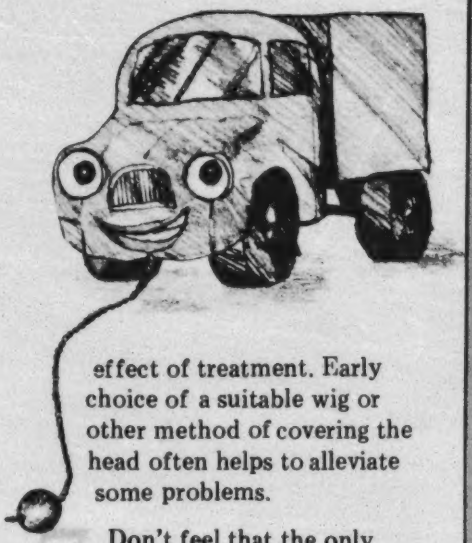
2 Keep brief home records of your child's health, including any unexplained symptoms, fever or suspected side effects, noting the incident, date, time, and duration. These should be reported to the physician, but are often difficult to remember accurately, with the stress of the clinic sometimes making recall especially difficult. This will give you a factual reminder of symptoms as they occur.

3 Keep your own brief records of clinic visits and medication, noting general blood count levels, treatment given at the clinic, and medication given at home. These are useful for your own reference and to inform your doctor should illness develop between clinic visits. Counts might determine whether medication should be stopped briefly or discontinued; and because certain drugs are not given during certain illnesses, these brief records can provide an additional service.

4 Accompany your child for bone marrows, treatments, and spinals. Some clinics encourage parents to help their child through these experiences. Although you may have trouble dealing with the treatment yourself at first, your support can do much to provide reassurance and comfort to a frightened child. In addition, it is easier to deal with a child's fears if you have been there when the procedure was performed and can discuss it with him.

5 Explain to your child that the clinic procedures are to help maintain his health and that the doctors don't want to hurt him, even though sometimes the procedures will hurt. Ask treatment team members to explain any new procedures or tests to your child or to you, so you can explain them. It is not necessary to frighten a child with too much information beforehand, but he should know enough so that he will be prepared. Above all, don't lie by saying it won't hurt if you know it will. A child who feels pain after being told there won't be any may lose confidence in your word.

6 Discuss the possibility of hair loss with your child and perhaps purchase a wig together or discuss other ways of handling this. If your child's hair begins to fall out, he may choose to wear a wig. Buying the wig before a lot of the hair has been lost will help to get a close color match and will allow your child to become accustomed to wearing a wig. If you have trouble finding a child-sized wig, treatment center staff should be able to help you. Both boys and girls can wear wigs, but some girls prefer to wear scarves and some boys to wear caps. Teenagers find hair loss particularly difficult; to them this



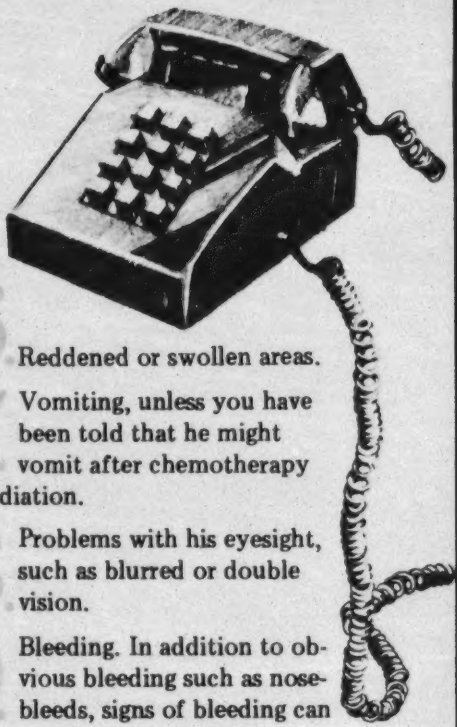
effect of treatment. Early choice of a suitable wig or other method of covering the head often helps to alleviate some problems.

7 Don't feel that the only time you can talk to treatment staff is during clinic visits, when you are already under pressure. You will probably have questions about your child and his disease from time to time. Conferences can be scheduled outside of clinic hours with members of the clinic. These are not uncommon, and can be arranged through the oncology nurses or social worker. To make the most of the conference, you may want to make a list of any questions you have and take it to the conference.

8 Be discrete when talking with other parents or with patients in the waiting room. Don't discuss aspects of your child's illness that you don't discuss with him.

Tips for Clinic Visits and Medical Procedures

When to Call Your Doctor



Ask your physician when he should be called. Call when you have questions or if you are unsure whether something should be reported.

In general, you should let a physician or other team member know if your child has any of the following:

1. A fever or other sign of infection, or just doesn't "look well" when he has a low white cell count. When his white cell count is adequate, you should report a fever or any other signs of infection that persist or become worse.

2. Exposure to a contagious infection, especially chicken pox or measles, unless he is known to be immune from prior exposure; or when he develops a contagious infection.

3. Persistent headaches, or pain or discomfort anywhere in the body.

4. Difficulty in walking or bending.

5. Pain during urination or bowel movements.

6. Reddened or swollen areas.

7. Vomiting, unless you have been told that he might vomit after chemotherapy or radiation.

8. Problems with his eyesight, such as blurred or double vision.

9. Bleeding. In addition to obvious bleeding such as nosebleeds, signs of bleeding can be seen in the stools (either red or black), in the urine (pink, red, or brown), in vomit (red or brown, like coffee grounds), or the presence of multiple bruises.

10. Other troublesome side effects of treatment, such as mouth sores, constipation (beyond 2 days), diarrhea, and easy bruising.

11. When your child is very depressed or you notice a sudden change in behavior.

You should also check with your physician when your child is due to receive any kind of vaccination or any form of dental care.

Common Medical Procedures

Evaluation and treatment of a young person with cancer involves a variety of diagnostic procedures. Many of these are repeated at intervals over the course of treatment to monitor progress and response to therapy. These procedures should be carefully explained to you and your child before they are carried out. If you have any questions, do not hesitate to ask your physician or another member of the treatment team.

Angiograms

Angiograms reveal blocking, deviation, or abnormal development of blood vessels, which may indicate the presence of a growing tumor. The blood vessels are injected with dye and then X-rayed. A similar type of study, *lymphangiography*, can be used when cancer involving the lymphatic system is suspected.

Biopsy

Biopsy is a surgical procedure used to determine whether tumor tissue is benign or cancerous. For this test, a small piece of tissue is removed from the tumor and then examined under a microscope to check for the presence of cancer cells. The tissue is examined by a pathologist, a physician who is an expert at identifying the changes in body tissue caused by disease. This microscopic study of the tissue confirms or rules out a diagnosis of cancer.

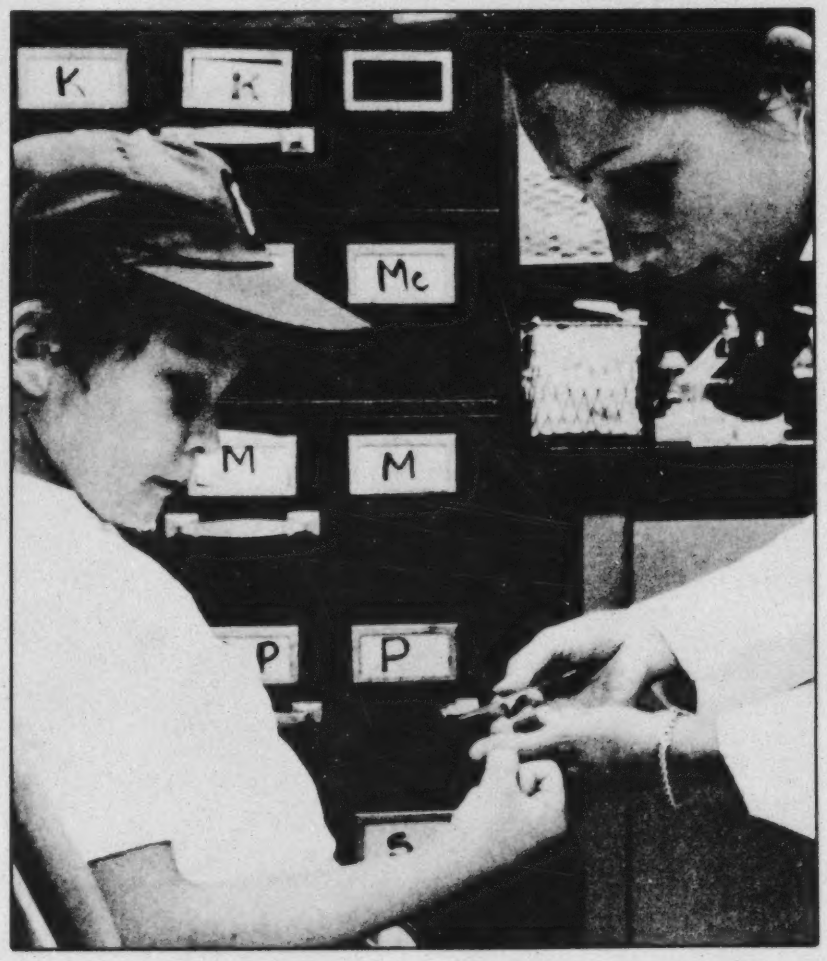
Blood Studies

Blood studies evaluate the young person's blood and the components of the blood using a variety of tests. The blood studied in these tests is obtained by drawing blood from a vein with a syringe or by a "fingerstick," in which a small prick is made in a fingertip and a few drops drawn off.

Different tests that may be performed to study the blood include:

White Blood Cell Count (WBC)

Blood cells ("blood smear") are stained on a slide and examined under a microscope. The white blood cells, those components of the blood which fight infection, are counted, and the number of those cells per cubic millimeter of



blood established. Young people receiving chemotherapy generally have a lower white cell count than normal. This test is also used to detect the presence of leukemic blasts.

Hemoglobin

Measurements are taken of the amount of hemoglobin, the substance in the red blood cell that carries oxygen and is responsible for the blood's red color. Lower amounts than normal of this substance in the red blood cells indicate anemia. If the patient shows a low hemoglobin, physicians may do other tests to find out why, and give medication (iron supplements in some cases) to correct it. A sudden appearance of anemia may suggest a relapse or be a side effect of chemotherapy.

Hematocrit

This is a measure of the amount of red blood cells, and is expressed as the percent of the whole blood that is made up of red cells. A low count may indicate anemia.

Platelet

The number of platelets (that component of the blood which helps stop bleeding in case of injury) per cubic millimeter of blood is counted. A platelet count below normal range may be due to relapse, side effects of medication, or infection. If platelets are low, more tests may be necessary to find out the reason.

Bone Marrow

Bone marrow (aspiration) evaluates the stem cells that mature into normal blood cells. The procedure is used to diagnose leukemia and to check the response to treatment. In young people with other cancers, it determines whether the disease has spread to the bone marrow.

Bone marrow aspirations in young people are usually done in the pelvis (hip bone). With the patient lying on his stomach and with a pillow under his pelvis, the area is cleaned with an iodine solution to kill skin bacteria. Then the skin is numbed with a local anesthetic and the bone marrow needle is put through the skin and into the spongy part of the bone. A sensation of pressure is felt; some patients also complain of pain. Once the needle is in place, marrow is quickly drawn into a syringe. This is the most painful phase, but lasts only a second or two.

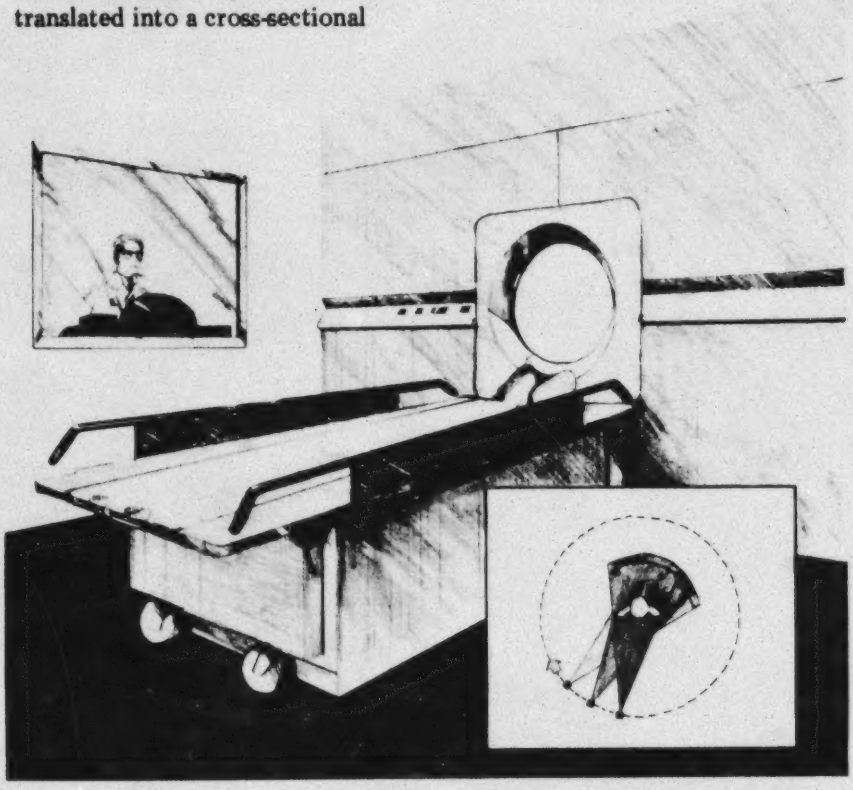
The entire procedure usually takes less than 5 minutes and is not dangerous, but it may be stressful to the patient. Attempts to reduce a patient's anxiety and get him to relax may reduce the pain of this procedure and certainly its stress. Usually there is only temporary tenderness at the site and the young person can get up and go immediately afterwards.

Computerized Axial Tomography

Computerized Axial Tomography (CAT scan) is a new X-ray technique for detecting masses in the body. While the young person lies still, a narrow X-ray beam directed by a computer revolves around him. In a matter of seconds the machine registers thousands of bits of information, which are translated into a cross-sectional picture on a viewing screen. The physician can also refer to a printout for more detailed analysis.

Lumbar Puncture

Lumbar puncture (L.P. or spinal tap) is used to determine whether cancer cells or infection are present in the cerebrospinal fluid



In Computerized Axial Tomography (CAT scan), a computer directs X-ray beams from a rotating disc at regular intervals. The beams travel through the portion of the body being studied onto a device that registers the beam's findings. The results are analyzed by a computer and the data appears as a three-dimensional image on a TV screen.

(CSF) that surrounds the brain and spinal cord. It is also used to deliver anticancer drugs directly to the brain and spinal cord.

An L.P. is done while the patient is lying on one side or sitting. In either instance it is very important that the patient be in a tight ball so the lower back is rounded and the backbone projects backward. After the young person is in position, a local anesthetic is applied to the lower back. The patient is held in a tight ball and the needle is inserted between the vertebrae into the fluid space around the spinal cord. A sample of CSF is collected and examined for blood and cancer cells, levels of sugar and protein, and can be cultured to check for infection. After the fluid is collected, medicines may be given through the puncture. As with bone marrows, this can be painful and produce anxiety in the patient. Some of this may be alleviated if the patient can learn to relax during the procedure.

Usually there are no aftereffects, but sometimes the young person may get a headache when sitting or standing. Sometimes the headache can be prevented by lying flat for about an hour after the procedure and by increasing fluid intake for 24 hours afterwards. Fortunately, headaches are uncommon and usually the young person can return to normal activity. When anticancer drugs are given into the spinal fluid, nausea and vomiting may occur. Antinausea medicines may be prescribed by your physician.

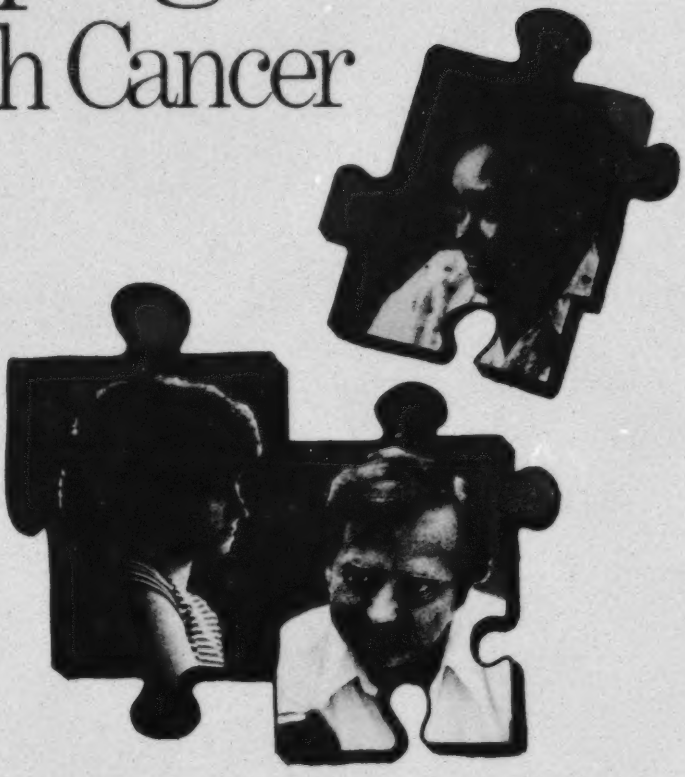
Scans or Radioisotope Studies

Scans or radioisotope studies are used to discover abnormalities in the liver, brain, bones, kidneys, and other organs. In these tests, chemicals that collect in particular organs can be "labeled" with a harmless radioactive material. The young person swallows the material or is injected with it. After a short waiting period, electronic devices are used to track the radioactive material as it collects within the body. Looking at how the material distributes itself in the body, the physician can then "see" whether an organ is functioning correctly or if it contains an abnormal mass or masses. Your child will not be radioactive after or during these tests.

Ultrasound Studies

Ultrasound studies determine the presence of tumors in the young person's body. Because tumors generate different "echoes" than normal tissue, sound waves above the range of human hearing can be bounced off tissue, and then changed electronically into images. Ultrasound is particularly effective in diagnosis because it can "recognize" masses that are not cancerous.

Coping with Cancer



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Dealing With the Diagnosis

Even though many parents suspect what the outcome of their child's diagnostic tests will be, the diagnosis confirming these fears comes as a shock. Initial explanations of the disease and treatment may be lost as parents try to come to grips with the reality that their child has cancer. This initial confusion is common, and repeated explanations of the diagnosis, treatment, and possible outcome of the disease may be necessary. Since this is a time when many important decisions must be made, as a parent you should not be hesitant or embarrassed about asking and reasking questions about your child's disease and its treatment. Treatment centers often provide printed materials that give further explanations about cancer and its treatment which allow parents to absorb details at their own pace. A selected list of such materials, including those available free of charge from the National Cancer Institute, begins on page 79.

Parents' Initial Reactions

Parents may experience many feelings upon hearing that their child has cancer. Common reactions are denial, anger, guilt, grief, fear, and confusion. These reactions are natural and may be a way of helping you cope with the necessity of accepting a situation that you want to change but cannot. It is important to remember, however, that this is a time when your child needs your support, and is particularly sensitive to your moods and feelings. Expressing these feelings too strongly may create problems for him. A child, particularly an older child, who senses that his parents do not want to acknowledge his disease, may try to protect them by not discussing his own feelings and fears. This feeling isolates him from an important source of support and may only increase his concerns, as he may imagine the situation to be far worse than it actually is.

Although the diagnosis is usually definite once the test results have been examined, parents occasionally ask for a second opinion from another physician. Your physician or treatment center can recommend someone to you, or you may wish to get a recommendation from another source. Second opinions may be useful for confirming the diagnosis and reas-

suring parents as to its accuracy and for confirming recommended treatment or exploration of another approach to treatment. However, once the diagnosis and treatment have been agreed upon by two physicians, seeking a third opinion may in fact reflect a parent's need to find another, more acceptable diagnosis. This puts an unfair burden on the sick child and delays treatment.

Accepting the Diagnosis

Gradually parents realize that their child has cancer and nothing can change it. At this point they begin to cope with the diagnosis and their feelings about it. Some parents become angry. Targets for this anger may vary, and can include God, themselves, the physician, or even the sick child for becoming ill. Because it is difficult to express anger at the sick child, spouses and healthy children can become the scapegoats for unresolved feelings. Parents sometimes lose their tempers. Letting the anger out may occasionally be helpful. It is important to remember, however, that other members of the family experience similar feelings. Realizing that some reactions stem from this anger and talking things through with family members, treatment staff, or others who can give support may help in dealing with these feelings.

Feelings of guilt may stem from thinking that the child's illness is retribution for the parents' past mistakes. Parents may worry about how they treated the child or whether the child should or

should not have received a certain vaccine. It may be difficult to accept that, despite all their efforts to understand the cause of their child's cancer, it will largely remain unexplained. One thing parents should remember is that, so far as scientists can determine, *nothing they did or didn't do caused their child's illness.*

Parents frequently blame themselves and their physicians for delays in diagnosis. All parents want to know when the cancer began, but there is no definite answer. The onset can be rapid or gradual. Because the early symptoms of cancer are often the same as those for common childhood illnesses, early diagnosis is sometimes very difficult—even for physicians. Furthermore, medical evidence suggests that in most cases of childhood cancer, the success of therapy depends more on the type of tumor and appropriate treatment than the time of diagnosis.

Telling Your Child

One of the most difficult decisions facing parents after diagnosis is what to tell their child. In the past, there were strong cultural tendencies to shelter children from painful realities. Today, there is general agreement that the patient should be told as much about his illness as his age allows him to understand. In fact, recent studies have shown that, even when children are not told about their disease, they learn its name and its implications within the first few months of treatment. It is virtually impossible to keep a child from the knowledge that he is seriously ill, as his environment has already told him he is: he takes special medicines and his parents are likely to show extra concern about his health. At home and at school, there are opportunities for him to overhear discussions about his condition. In the hospital, he may see and talk to other children with the same disease.

The question, then, is not whether to talk about the diagnosis, but rather how to let the child know that his concerns are shared and understood and that you are willing to talk about these things with him. The single most important and basic approach is gentle, honest communication. Failure to answer a child's question in an honest fashion undermines the parent-child relationship at a time when the child desperately needs to communicate with his parents.

As a parent, you are the best judge of your child's moods. But you may want to keep in mind that, just because your child does not talk about his illness and the fears related to it (including death), you cannot assume he

does not have these fears. The child who knows his illness is more serious than the usual childhood illness is undoubtedly afraid, and secrecy tends to isolate him and increase his fears.

Exactly when and what to tell your child will depend on his age and maturity and your attitudes. You may prefer to tell the child yourself, with or without the physician present, or you may want the doctor to do it. Use the method that makes you feel most comfortable.

Age-related Concerns of Children

Your physician or other members of the treatment team may be able to help you determine what and how to tell the child. Some of this will depend on the child's age. In general, toddlers need only be told that they are sick, that they have to take medicine to get better, and that needles hurt, but only for a minute. Separation, abandonment, and loneliness are especially frightening to children under 5. They need to be reassured that, even if you have to leave for a while, you will be back. Children between the ages of 6 and 10 and perhaps as young as 5 have fears relating to physical injury and bodily harm. They understand that theirs is no ordinary illness; it is very serious and very threatening. Thus, they need to know that they have cancer, a serious but treatable disease. They may also be told that the cause of cancer is unknown, that they will require a lot of medicine, and that it may take some time before they really feel well again. Much can be said with honesty and hope.

Older children and adolescents are old enough to understand their diagnosis and treatment, and also its implications. They may equate

cancer with dying, and they need to know not only about their diagnosis and treatment, but also that cancer can often be successfully treated, and about treatment advances and increased survival rates.

To these young people, the impact cancer and its treatment will have on their normal activities, appearance, and relations with peers may also be especially important.

Reassuring the Child

Whatever you tell your child about his illness, he may bring up the issue of death and his fears of it. Be prepared to cope with questions about death, even if they are painful. Refusing to discuss death may deny your child an outlet for some strong and possibly frightening feelings, and it will deny you the opportunity to comfort or to reassure him. In addition to discussing his feelings and fears it is important to stress to all young people with cancer the fact that cancer can be treated, that research for better methods is ongoing, and that new treatments are becoming available all the time.

Finally, young people of all ages tend to feel guilt and anger at the time of a severe illness. Guilt feelings may stem from the often subconscious feeling that disease is a punishment for being bad. Your child, therefore, needs *frequent* reassurances that he has done nothing wrong and is loved. The child may be angry at himself or at you for letting his illness happen. It is important for you to

remember that even when your child is angry with you, he still loves you.

Many parents fear they will say something wrong that will upset their child or cause undue distress. In honest discussions this rarely happens. Even if the child is initially upset or angry, he will eventually benefit from the sharing of his concerns with those who love him.

By handling the situation as

openly as possible, the parent and child are free to resume as normal a life as possible. Shared awareness among the young person, parents, and medical personnel frequently has a soothing effect. The child seems happier knowing about the disease than fearing the unknown. Medical care is more successful because he can actively participate. Parents do not carry the extra burden of concealing the truth. Despite the uncertainties and the heartaches, everyone becomes more comfortable with the disease and with the future.

In addition to talking with their parents and caregivers, young people with cancer may want to read about cancer and about hospitalization. Such materials are limited, but a selected list appears in the list of additional reading materials beginning on page 79.

Telling the Brothers and Sisters

The diagnosis of cancer affects the entire family. For the siblings, the initial period can be a time of confusion and fear. Children, even young ones, are sensitive to what is happening. They are aware of a brother's or sister's hospitalization, and of trips to the doctor and to the clinic. They notice their parents crying and trying to comfort one another. They may overhear parts of conversations that are difficult to understand. Children often conspire to figure out what is going on. Pieces of information are gathered, pooled, and analyzed. Because of this, it is important to take time early in the diagnosis and treatment process to have an honest discussion of the situation with the siblings. Encourage them to ask questions and answer these as honestly as possible. Explain the facts about cancer keeping in mind the age and maturity of each child and update the information periodically as the siblings and patient get older and are able to understand more. If the siblings are very young, it may be enough to say that their brother or sister is sick, will have to stay in the hospital for a while, and will need to take medicine for a long time. Older children will require more detailed information about cancer and its implications. Siblings should be prepared for physical changes in the patient, such as hair loss or amputation. If you wish, the doctors or nurses who care for the patient may be called upon to explain the diagnosis, prognosis, and treatment to the siblings or to discuss it with the entire family.

All of the children need to know that cancer is not contagious and that they will not become sick from contact with the patient. They need to be reassured that they are healthy themselves and that the possibility of cancer running in the family is highly unlikely.

Siblings also need to be told emphatically that they are in no way responsible for the illness. Angry outbursts, such as "Drop dead!" or "I hate you," which are said by all normal children at one time or another, frequently haunt a child when he learns about his sibling's illness. Feelings of guilt or wrongdoing need to be dealt with immediately. Failure to do so may result in problems later on.

Continuing Life

One of the challenges facing the family of the child with cancer is maintaining a normal life. This is not always an easy task, particularly during moments of high stress such as at the time of diagnosis and during hospitalizations and relapses. Even when treatment is going successfully, the lives of the patient and family members are influenced by the disease and its treatment and side effects. Schedules are rearranged to accommodate hospitalization or clinic visits, family members may be separated, siblings may feel neglected. Everyone may be worried or tense.

Despite all this, the continued development of family members demands that life continue as normally as possible under the circumstances. To see that this happens, the sick child should be treated as normally as possible, the needs and feelings of the patient's siblings attended to, and pre-diagnosis sources of support kept open for both the parents and the child. In addition, new sources of support, such as other parents of children with cancer and treatment team members, can help parents cope.

The Parents

To cope with the child's illness and the changes this brings in your own life, you may want to consider the following suggestions:

1. Make a special effort to find private times to communicate with your spouse, or, if you are a single parent, with others close to you. Don't allow all your discussions to revolve around the sick child. Make time to do things you enjoyed doing together before your child became sick.

2. Find ways to reduce the frustration you may feel when clinic visits require waiting for procedures, test re-

sults, or consultations with physicians. When your child is hospitalized, try to make it as easy on yourself as possible. Bring something to read or do while the child is sleeping or doesn't need your individual attention.

3. If work schedules permit and the distance between hospital and home is close enough, you and your spouse may alternate staying with the hospitalized child. Weekends may be a good time for a switch: the parent who has been at home or work can stay at the hospital and the other parent can spend time at home with the other children and rest. It also allows both parents to become familiar with the child's life in the hospital and various aspects of treatment. This reduces the gap that may grow between parents when one becomes much more actively involved in the treatment than is the other. If you are a single parent, other family members or friends who are close to the child may be able to stay at the hospital occasionally so you can rest.

4. Don't hesitate to turn to treatment staff for support. Most treatment centers have psychologists, psychiatrists, social workers, nurse clinicians, or chaplains available to talk over special concerns.

5. You may want to look for other sources of support. Talk to other parents of children with cancer informally in the hospital or clinic. Your treat-

ment center may have a parents' group supervised by a staff member for more formal discussions. In addition, organizations outside the center may also exist. Such groups may provide support and information on how others have dealt or are dealing with situations you are facing. One national group, the Candlelighters (see "Sources of Information, Support, and Assistance" for a full description),

has local chapters. Treatment center staff may be able to help you locate such a group.

When your child is in remission, it may be tempting to put all thoughts of the cancer out of your mind. And, indeed, this is a good time to get a rest from it and focus your attention on other segments of your life. However, this is also a good time to clear up any misconceptions about the cancer that the patient, siblings, or other family members and friends may have.

This is particularly true for the patient and siblings when treatment has been a lengthy process. You may need to initiate discussions to update information if you feel that this has not happened naturally during the course of treatment and that the child is concerned but reluctant to raise questions.

The Patient

Although the diagnosis of cancer will change your child's life for a time, he still has the same needs as other young people—for friends, school, and the activities he enjoyed before he became sick. You can help your child by encouraging him to continue his "normal" life as much as possible.

Friendships may be maintained during hospitalization or when your child is sick at home through letters or telephone calls.

School

For the school age child, continuing with school is vital. School is the major activity of children his age, and continuing to attend school will reinforce his sense of well-being. Furthermore, it prevents him from falling behind others his age in learning and in the emotional development that comes from participating in school and school activities. When your

child is hospitalized, a special hospital school program may be available. If he is receiving frequent treatments or is too ill to attend school while at home, a home tutor may be available through the school system (the treatment center may be able to help you arrange for this). But home tutoring should be undertaken with the understanding that it is directed toward easing the eventual return to school.

When the young person returns to school, the teachers, counselor, school nurse, and principal may need information about the cancer and its treatment, any absences necessary for treatment, and any restrictions on activity. Teachers should be encouraged to give normal, equal attention in-

stead of granting special favors that his condition does not warrant. *Students with Cancer: A Resource for the Educator*, a publication for school personnel designed to ease your child's return to school, is available from the National Cancer Institute (see listing in "Additional Reading Materials").

Both you and your child may be anxious about his return to school. He may be uneasy about how classmates will react to any change in appearance, such as hair or weight loss, weight gain, or loss of a limb through amputation. You may find yourself reluctant to allow him to return because you are afraid he will become ill or you find separation difficult. Both reactions are common. But he should return to school. Accept his fear of rejection and try to help him deal with it. Most young people and parents find that their fears are unwarranted. Usually, classmates accept the patient and his condition and he gains a sense of self-confidence by resuming his former role as a student. Since classmates may have questions about the child's cancer and any changes in appearance, you may want to help him anticipate these questions and answers to them.

Discipline

Discipline is important to the normal development of all children. This is no less true when they have cancer. However, the special circumstances of these children's lives may make maintaining discipline more difficult. Having seen their child ill and in pain, parents may attempt to make up for this by giving extra presents or allowing behavior they would not tolerate in another child. They may find it difficult to discipline the child with cancer because of the uncertainty of his future. Although it is true that for many of these young people the future is uncertain, and some will die, discipline is an important part of seeing that the quality of life is maintained.

It may also be tempting to overprotect your child, to keep him with you and away from situations you cannot control. This may deny him the opportunity to participate in normal activities necessary for his growth and development.

Some parents say that discipline and the setting of boundaries for behavior and activity is all the more difficult because they do not know what they can reasonably expect of their child. Ask your physician or other members of the treatment staff whether the child's therapy may be making him be-

have differently, and if any limits should be set on his activities. If the child should avoid "contact" sports because his platelet count is low, you will want to see that he avoids them. But if there is no reason for him not to go skateboarding or participate in sports, denying him this may be overprotection on your part at a time when he should be enjoying normal activities. Some medications may make him feel tired. In these cases he may not have the energy to participate in some functions. Some children, however, may occasionally complain of being tired to avoid chores they do not enjoy or activities they are reluctant to try. When you know what to expect of him, you will be able to treat him as you would any other child.

Adolescents

Many teenage patients complain that their parents are overprotective. Although this is a common cry of adolescents, it may be especially true with teenage cancer patients who are at a stage in their lives when they are naturally striving for independence, but have a disease which forces them to be dependent on you and caregivers. Adolescents' attempts to achieve independence and make some of their own decisions should be encouraged within the limits set out by medical personnel.

With adolescents, certain special questions may arise. Those with driver's permits may want to go to the clinic alone or with a friend. Frustration over the disease-related dependence may increase their need to rebel against authority figures, which in this case could include physicians and other hospital personnel as well as you and other family members.

As with many teenagers, the questions of sexuality and drug use (including alcohol) may arise.

In general, these are neither more nor less complex than when these issues are faced by adolescents who do not have cancer. In terms of drug use, however, the issue of marijuana may take on extra importance if the patient is on

chemotherapy and has heard that marijuana helps prevent vomiting after chemotherapy. There is some evidence that THC, the active ingredient in marijuana, may be effective in controlling chemotherapy-induced nausea and vomiting. Researchers at various treatment centers are studying the effectiveness and side effects of oral THC capsules.

Siblings

Siblings of cancer patients may have many different feelings about the patient, his illness, and the attention he receives. While sympathizing with their brother or sister who is ill, they may still feel some resentment and believe that they are being neglected. In many cases, this is true. During times of hospitalization or when the patient is not feeling well, attention may focus on him. As parents, you may not be able to pay as much attention to his siblings as you did before. You may have to miss school functions or ball games in which the siblings are participating. You may have little emotional reserve left after dealing with your sick child to talk with his siblings about their concerns, to play with them, or help with their homework.

When you do have the energy, try to make special time for the siblings. Encourage them to become involved in outside activities and make a point of recognizing their achievements. When you can, make plans to spend time alone with them and do things that interest them.

Others may focus special attention on the sick child. It is not unnatural, then, for siblings to resent the "privileged status" of the sick child in the family, neighborhood, and school, and the lack of attention to their own needs. Talking with siblings about the special attention paid to the sick child, letting them know that feelings of resentment are natural, and enabling them to share in the family crisis will encourage healthy growth and maturity. Efforts should be made to give equal attention, or explanations when this is not possible.

One way to help them to understand their brother's or sister's illness is by involving them in the treatment. Older children in particular welcome the opportunity to be taken into their parents' confidence and will often respond in helpful ways. Finding things for them to do for their sick brother or sister, or their worried parents, gives many young people a sense of belonging and usefulness that

might otherwise be lacking in the family's focus on cancer.

Siblings may accompany you to the clinic when the patient gets his treatment or, if possible, visit the patient when he is hospitalized. This will allow them to see for themselves what the hospital, clinic, and treatment are like. If this is not possible because of distance, try to describe the setting and situation. Siblings may need such concrete experiences or explanations to prevent the construction of fantasies about the hospital and the hospital experience. Fantasies may range from fearing that the patient is being tortured to believing that he is having a good time; siblings may be terrified or jealous.

Remember, the patient's brothers and sisters may be asked questions about the illness by schoolmates or others in the community. They should have enough information to answer these questions. In fact, you might want to help them anticipate questions or comments and discuss possible answers.

Behavior Changes in Siblings

Behavior changes among siblings of young people with cancer are common and can indicate that they are having trouble dealing with the situation. They may become depressed, have headaches, or begin to have problems in school. If necessary, counseling can help them cope with their feelings, and treatment center staff can help with this. If their teachers are aware that a brother or sister has cancer and that this might affect the student, teachers can alert you if problems arise at school.

Remember that siblings, like all children, don't care about tomorrow and want equal treatment and attention today. It helps to appreciate them as individuals and to make a special effort to keep in touch with their needs.

Family and Friends

A diagnosis of cancer affects not only the patient's parents and siblings, but also the grandparents, other relatives, and family friends. Ideally, these people can provide support and assistance. They can babysit and spend time with the

siblings, stay with the sick child to relieve you, or assist in the many practical problems that arise when a household must continue to function under stress.

Unfortunately, they are not always able to do this. Grandparents may feel particularly lost and helpless, since they are concerned about their grandchild and at the same time cannot stop the suffering of their own child. If grandparents do not understand and accept the situation, you may find yourself in the difficult position of dealing with your own emotional difficulties while attempting to support the grandparents. Treatment team members can help, for instance, by offering to explain the child's condition to the grandparents. Being allowed to participate in meetings of parents' groups may also help grandparents deal with their feelings about the child's illness.

Each family has its own way of relating to relatives, friends, and neighbors. Above all, initial honesty is of real value in the long-term handling of any problems. People want and need to help, but they may need assistance from you to do so. They will need information about the disease and its treatment. Some may have to be told such basics as the fact that cancer is not contagious.

In general, you and your sick child must take the lead in showing others how you want to be treated.

You may need to point out to family and friends that paying too much attention to the patient, or indulging him, does not help him. For yourself, you may need to show others that you want to be treated as you were before, and, although your time may be limited, you would like to be included in activities you previously enjoyed together.

Your employers may also need to be told about your child's sickness so they can understand the reason for requests for time off from work. If you feel it is necessary, the child's doctor may write your employer and explain the situation.

Finally, in their efforts to help, people will give all sorts of advice. If their comments are confusing or upsetting, make a point of discussing them with medical personnel.

Finances

The cost of your child's treatment may cause additional pressure in an already tense situation. The desire to have the best in care may be offset by fear about the costs and how they will be met. As soon as financial questions arise, ask your doctor or the social worker for help.

Because health and life insur-

ance questions can influence major health decisions, you'll need a clear understanding of the coverage your policies offer. Caregivers, particularly medical social workers, can clarify individual policies and help you fill out forms.

You should also keep complete records; store your bills and insurance forms together for easy reference at tax time. Keeping track of bills, your payments, and insurance payments by date and type of charge will simplify this further. Current records of bills and payments can be kept by listing them on a single sheet using the following format suggested in Nina Cottrell's *Coping at Home with Cancer* (listed in the section on additional reading materials):

Date	Paid	Bill From	Total Charge	Ins. Paid	We Paid
7/1/78	Ch. 213	XYZ Surgery	$408.00	$365.42	$42.28

Treatment center staff may also be able to help you with other costs associated with cancer treatment. Check with them to see if you are eligible for special rates for parking or food at the hospital. If your child is hospitalized or needs daily treatment away from home, lodging costs for parents may be substantially reduced if a Ronald McDonald House (described in "Sources of Information, Support, and Assistance") is available or other special arrangements have been made. Medical social workers may be familiar with other programs, such as those of voluntary cancer-related organizations (including those listed in "Sources of Information, Support, and Assistance") or state or local programs, that may be able to assist you.

Sources of Information, Support, and Assistance

Candlelighters

Candlelighters is a national organization of parents whose children have or have had cancer. Now numbering over 100 chapters and affiliates in 40 states, the organization formed almost simultaneously in Washington, D.C., Florida, and California in 1970. The name is taken from the saying that "It is better to light one candle than to curse the darkness."

Not all groups are called Candlelighters; the Wisconsin organization, for example, is LODAT (Living One Day At a Time).

The Candlelighters Foundation was created in 1976. Headquartered in Washington, D.C., it maintains communications between parents and professionals through quarterly newsletters and between groups through bimonthly newsletters. It publishes a teens newsletter and an annual cumulative bibliography for parents, operates a parent information service, offers information and assistance in forming new groups, and makes available a variety of handbooks to such groups.

Family support groups under the aegis of Candlelighters have many functions, including:

- exchanging practical information and ways of dealing with common problems;
- providing an outlet for the frustrations of those under stress through informal self-help sessions;
- offering a social outlet for parents and siblings, reducing the sense of isolation often imposed by cancer;
- disseminating information through meetings featuring medical speakers, psychologists, or insurers; and,
- directing families to professional counseling.

Some of the local chapters have such services as a toll-free hotline

and a program that provides visits to the oncology areas of hospitals for the parents of newly diagnosed patients.

For more information on Candlelighters chapters and programs, contact:
Candlelighters Foundation
123 C Street, S.E.
Washington, D.C. 20003
(202) 659-5136 (days)
(202) 544-1696 (evenings)

American Cancer Society

The American Cancer Society (ACS) is a national voluntary organization offering programs of cancer research, education, and patient service and rehabilitation.

Local ACS units conduct service programs for cancer patients and their families, including:

- information, counseling, and guidance concerning ACS services, community health services, and other resources;
- equipment loans for care of the homebound patient;
- surgical dressings; and,
- transportation to and from treatment.

Depending on the facilities and resources of the units, these programs may be expanded to include home health care, blood programs, social work assistance, medications, and a complete rehabilitation program.

For further information, consult local telephone directories for the closest ACS office or contact:
American Cancer Society
National Headquarters
777 Third Avenue
New York, New York 10017
(212) 371-2900

Leukemia Society of America, Inc.

Financial assistance and consultation services for referrals to other means of local support are offered by chapters of the Leukemia Society of America to cancer patients with leukemia and allied disorders. Financial coverage is reserved for outpatients and pays up to $600 per patient per year of costs not covered by other sources. The program includes payment for drugs used in the care, treatment, and/or control of leukemia and allied diseases; laboratory costs associated with blood transfusion; transportation; and up to $300 of costs for X-ray therapy for early Hodgkin's disease and up to $300 of costs for cranial radiation for children with acute lymphocytic leukemia.

For more information about the program and its local chapters, contact:
Leukemia Society of America, Inc.
211 East 43rd Street
New York, New York 10017
(212) 573-8484

The Cancer Information Service is a toll free telephone inquiry system that supplies information about cancer and cancer-related resources to the general public, cancer patients and their families, and health professionals. CIS is administered by the National Cancer Institute. Most CIS offices are associated with Comprehensive Cancer Centers, which are special research and treatment centers recognized by the National Cancer Institute.

CIS offices do not diagnose cancer or recommend treatment for individual cases. They do provide support, understanding, and rapid access to the latest information on cancer and local resources. Telephone information may be supplemented by printed materials. All calls are kept confidential and you do not need to give your name.

A list of CIS offices by state with regional toll-free numbers follows:

Alabama:	1-800-292-6201
Alaska:	1-800-638-6070
California: (from Area Codes 213, 714, and 805 only)	1-800-252-9066
Connecticut:	1-800-922-0824
Delaware:	1-800-523-3586
District of Columbia:	636-5700
Florida:	1-800-432-5953
Georgia:	1-800-327-7332
Hawaii: Neighbor Islands: Ask operator for	Oahu: 524-1234 Enterprise 6702
Illinois:	800-972-0586
Kentucky:	800-432-9321
Maine:	1-800-225-7034
Maryland:	800-492-1444
Massachusetts:	1-800-952-7420
Minnesota:	1-800-582-5262
New Hampshire:	1-800-225-7034
New Jersey (Northern):	800-223-1000
New Jersey (Southern):	800-523-3586
New York State:	1-800-462-7255
New York City:	(212) 794-7982
North Carolina:	1-800-672-0943
North Dakota:	1-800-328-5188
Ohio:	1-800-282-6522
Pennsylvania:	1-800-822-3963
South Dakota:	1-800-328-5188
Texas:	1-800-392-2040
Vermont:	1-800-225-7034
Washington:	1-800-552-7212
Wisconsin:	1-800-362-8038

FOR ALL OTHER STATES
800-638-6694

Ronald McDonald Houses

The first Ronald McDonald House opened in 1974 as a place where out-of-town families can stay while their children are being treated at the Children's Hospital of Philadelphia. Since that time, other houses have opened in other major cities. In general, a Ronald McDonald House is available for families of seriously ill children and provides lodging at economical rates.

For further information about the Ronald McDonald House program, contact.

Mr. A. L. (Bud) Jones
Ronald McDonald House
Coordinator
c/o Golin Communications, Inc.
500 North Michigan Avenue
Chicago, Illinois 60614
(312) 836-7100

Home Care for the Dying Child

While treatment efforts are successful for many children with cancer, this is not always the case. When treatment is not successful and the child's disease becomes terminal, some parents may wish to have him die at home rather than in the hospital. The patient may also prefer it. Parents who have taken their child home have shown that it is possible to provide quality care for their dying child when assisted by nurses, doctors, and other health professionals.

A home care program for children may exist in your area, but if one doesn't, you and the treatment center or a home health agency may have to work out the arrangements necessary for you to successfully care for your child. Coordination between parents and health care personnel is essential to success in caring for dying children. A home care nurse can help parents care for their child, help acquire any necessary equipment such as hospital beds or wheelchairs, and provide emotional support for parents. Basic information growing out of a research project on home care is available and may help parents who are interested in such a program. The two texts, *Home Care for Dying Children: A Manual for Parents*, and a nurses' manual, *Home Care: A Manual for Implementation of Home Care for Children Dying of Cancer*, may be purchased from:

Research Center
School of Nursing
University of Minnesota
3313 Powell Hall
500 Essex Street, S.E.
Minneapolis, Minnesota 55455

Glossary

Acute: Occurring suddenly or over a short period of time.

Adjuvant Chemotherapy: The use of anticancer drugs after surgery in patients whose cancers are most likely to recur.

Alopecia: Hair loss.

Anemia: A condition in which blood is deficient in red blood cells, hemoglobin, or total volume of red blood cells.

Antimetabolite: Anticancer agents that closely resemble substances needed by cells for normal growth. The tumor cell uses the drug instead, and "starves" for lack of proper substance.

Benign Tumor: A noncancerous growth that does not spread to other parts of the body. Outlook for recovery is favorable with treatment.

Biopsy: The removal and microscopic examination of tissue from the living body for purposes of diagnosis.

Blast Cells: An immature stage in cellular development before appearance of the definitive characteristics of the cell.

Blood Typing and Cross Matching: The blood cells contain factors which are not the same in all people. Before a transfusion can

be given, blood samples from the donor and recipient are typed, or classified (type A, B, AB, or O). Once the two blood samples have been typed, they are cross matched to be absolutely sure that they are compatible. This is done by placing red cells of the donor in a sample of the recipient's serum, and red cells of the recipient in a sample of the donor's serum. If the blood does not "clump," or agglutinate, the two bloods are compatible. Techniques for typing white blood cells and platelets are similar, but more complex. (See HL-A.)

Bone Marrow: The marrow is the spongy material which fills the cavities of the bones and is the substance in which many of the blood elements are produced. In order to determine the condition of the marrow, a doctor may take a small sample from one of the bones in the chest, hip, spine, or leg. Such examinations are performed with the help of local anesthesia.

Bone Marrow Transplant: Procedure in which a patient's bone marrow is destroyed by chemotherapy or radiotherapy and replaced with new bone marrow from a donor, usually a sibling with identical HL-A (Human histocompatibility antigens) to the patient's.

Cancer: A general term for about 100 diseases characterized by uncontrolled, abnormal growth of cells.

The resulting mass, or tumor, can invade and destroy surrounding normal tissues. Cancer cells from the tumor can spread through the blood or lymph (the clear fluid that bathes body cells) to start new cancers in other parts of the body (metastases).

Carcinogen: A chemical or other agent that causes cancer.

Carcinoma: Cancer of the tissues which cover or line the body surface and internal organs.

CAT Scan *(computerized axial tomography)*: Diagnostic X-ray procedure in which a computer is used to generate a 3-dimensional image.

CBC *(complete blood count)*: A series of tests to examine components of the blood. The tests are useful in diagnosing certain health problems and in following the results of treatment.

Chemotherapy: Treatment with anticancer drugs.

Chronic: A term that is used to describe a disease of long duration or one that is progressing slowly.

Clinical: In general, pertaining to observation and treatment of patients. Clinical research is a term applied to the study and treatment of patients.

CNS *(central nervous system)*: Refers to the brain and spinal cord.

Combination Chemotherapy: The use of two or more anticancer medications for treatment of an individual cancer patient.

Combination Therapy: The use of two or more methods to treat an individual cancer patient; e.g., surgery and X-ray.

Culture: A laboratory procedure in which micro-organisms contained in samples of blood, secretions, or other body fluids are cultivated in special nutrients; used to determine the presence and type of infectious agents.

DNA *(deoxyribonucleic acid):* The basic material of life. DNA is a long, chain-like chemical found in the nucleus of all cells. The segments of the chain are the genetic code that guides the development of every cell.

Erythrocytes: Red blood cells. Their main protein component, hemoglobin, carries oxygen from the lungs to all parts of the body.

Gamma Globulin: A class of protein components of the blood containing antibodies effective in defending the body from certain micro-organisms.

Gastrointestinal: Pertaining to the digestive tract, which includes the mouth, throat, esophagus, stomach, small intestine, large intestine, and rectum.

Granulocytes: One type of white blood cell that destroys invading bacteria.

HL-A: Human histocompatibility antigens. These antigens appear on white blood cells as well as cells of almost all other tissues and are analogous to red blood cell antigens (A, B, etc.). By typing for

HL-A antigens, donors and recipients of white blood cells, platelets, and organs can be "matched" to insure good performance and survival of transfused and transplanted cells.

Hematologist: A physician specializing in the study of blood diseases.

Hematology: The study of blood and blood forming organs.

Hemoglobin: The iron-protein component in the red blood cells which carries oxygen to the tissues.

Hemorrhage: A general term for loss of blood, often profuse, brought about by injury to the blood vessels or by a deficiency of certain necessary blood elements such as platelets.

Hyperalimentation: Intravenous administration of nutrients, bypassing the gastrointestinal tract. It is also called total parenteral nutrition (TPN).

Immune System: The body's system of defenses against disease, composed of certain white blood cells and antibodies. Antibodies are protein substances that react against bacteria and other harmful material.

Immunology: Study of the body's natural defense mechanisms against disease.

Immunotherapy: An experimental method of treating cancer that uses substances that stimulate the body's immune system.

Infection: Refers to the invasion and multiplication of disease-producing organisms in the body.

Informed Consent: Refers to the permission given by a person before surgery or other kinds of treatment. The patient, or a parent or guardian, must understand the potential risks and benefits of the treatment and legally agree to accept those risks.

Intramuscular (IM): Refers to the injection of a drug into muscle tissue where it is absorbed into the bloodstream.

Intravenous (IV): The administration of a drug or fluid directly into a vein.

Intravenous Pyelogram (IVP): An X-ray examination of the kidneys, that depends on accumulation and visualization in the kidney of a special substance that is injected into a vein.

Isotopic Scan: A diagnostic procedure for examining the brain, bones, and other organs. In this procedure, a radioactive substance is introduced intravenously, collects in certain organs, and is then studied by special scanners that detect radioactivity.

Leukocytes: White blood cells.

Lumbar Puncture: A diagnostic procedure that involves taking and examining a sample of spinal fluid.

Lymph: A nearly colorless fluid that bathes body cells and moves through the lymphatic vessels of the body.

Lymph Nodes: Bean-shaped structures scattered along vessels of the lymphatic system. The nodes act as filters, collecting bacteria or cancer cells that may travel through the lymphatic system.

Lymphangiography: An X-ray procedure using a radio-opaque dye to examine the lymph system.

Lymphatic System: Circulatory network of vessels carrying lymph, the almost colorless fluid that bathes body cells, and the lymphoid organs such as the lymph nodes, spleen, and thymus, that produce and store infection-fighting cells.

Lymphoma: A tumor of the lymphatic system.

Malignant: Tending to become progressively worse; in the case of cancer, it implies ability to invade, disseminate, and actively destroy normal tissue.

Metastases: Cancer growths that started from cancer cells shed by a primary cancer arising in another part of the body.

Monocytes: One type of white blood cell that destroys invading bacteria.

Neutrophils: A type of white blood cell that plays a major role in the body's defense against bacteria, viruses, and fungi.

Oncologist: A physician who specializes in cancer.

Oncology: The study of physical, chemical, and biological properties and features of cancer.

Ostomy: A suffix which refers to a surgically created passage connecting an internal organ with the skin or other internal organs.

Pathologist: A physician who interprets and diagnoses the changes caused by disease in body tissue.

Petechiae: Tiny localized hemorrhages from the small blood vessels just beneath the surface of the skin.

Plasma: The liquid portion of the blood which contains numerous proteins and minerals and is necessary for normal body functioning.

Platelet: One of the main components of the blood that forms clots that seal up injured areas and prevent hemorrhage.

Port: Well-defined area mapped out for radiation.

Prognosis: An estimate of the outcome of a disease; a prediction.

Rad: A unit of measurement for radiation.

Radiation Therapist: A physician who has had additional specialized training in using radiation to treat human disease.

Radiation Therapy: Treatment using high energy radiation from X-ray machines, cobalt, radium, or other sources.

Radiation Therapy Technologist: A specially trained technician who assists the radiation therapist in giving external radiation treatments.

Radiologist: A physician with special training in reading diagnostic X-rays.

Red Blood Cells:	Cells that carry oxygen to all the various organs and tissues of the body.
Relapse:	The reappearance of a disease after a period when symptoms had lessened or ceased.
Remission:	The decrease or disappearance of cancer symptoms. Also the period during which this occurs.
Sarcoma:	A cancer of connective tissue such as bone, cartilage, fat, muscle, nerve sheath, or blood vessels.
Toxicity:	The quality of a substance which causes ill effects.
TPN *(total parenteral nutrition)*:	The procedure in which nutrients are supplied directly to the bloodstream.
X-rays:	High energy radiation used in high doses to treat cancer or in low doses to diagnose the disease.

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Additional Reading Materials

Patient Information

1. Hospital Days—Treatment Ways. J. Warmbier; E. Vassy. 1978. 28 pp; coloring book.

The hematology-oncology coloring book is designed to familiarize pediatric oncology patients with some of the hospital diagnostic and treatment procedures that they may observe or experience. Parents are encouraged to explore the book with their child, allowing the child to express his feelings about the pictures. To assist parents in this interaction, a guide to the illustrations is provided.

Cost: free.

Source: National Cancer Institute
Office of Cancer Communications
Bldg. 31, Room 10A18
9000 Rockville Pike
Bethesda, MD 20205.

2. A Story About Cancer. J. A. Dobos; P. S. Tharp. 1978. 12 pp; coloring book.

Designed to help children cope with and express their feelings and fears about a parent who has cancer, the coloring book explains tumors, surgery, radiotherapy, chemotherapy, and family psychosocial problems.

Cost: mailing charges.

Source: Cancer Center of University Hospitals
At-Home Rehabilitation Program
2074 Abington Rd.
Cleveland, OH 44106.
Telephone: (216) 444-3783.

3. A Story About Leukemia to Color. P. S. Tharp; J. A. Dobos. 1978. 12 pp; coloring book.

The coloring book is designed to help pediatric patients explore their feelings and fears about leukemia.

Cost: mailing charges.

Source: Cancer Center of University Hospitals
At-Home Rehabilitation Program
2074 Abington Rd.
Cleveland, OH 44106.
Telephone: (216) 444-3783.

4. There Is a Rainbow Behind Every Dark Cloud. 1978. 96 pp; book.

Written and illustrated by children for children who have leukemia or other life-threatening illnesses, the book discusses the medical and emotional experiences these patients will encounter. Designed as a tool to help the child deal with his fears, the emphasis is on living in the present and healing oneself by maintaining a positive attitude.

Cost: $6.95.

Source: Center for Attitudinal Healing
19 Main St.
Tiburon, CA 94920.
Telephone: (415) 435-5022.

5. You and Leukemia: A Day at a Time. L. S. Baker. Rev. 1978. 205 pp; monograph.

This handbook on childhood leukemia, addressed to children over nine or ten years of age, was developed during the author's junior year at Mayo Medical School. It covers the pertinent facts about this kind of cancer: symptoms, diagnosis and treatment, and complications. Chemotherapy drugs are listed individually and their possible side effects detailed. Illustrations reinforce the text throughout and blank pages are provided for patients to record their own treatment programs or to draw pictures.

Cost: $7.95.

Order No. ISBN 0-7216-1495-7.

Source: W. B. Saunders Co.
W. Washington Sq.
Philadelphia, PA 19105.
Telephone: (215) 574-4700.

6. What Happened to You Happened to Me. M. A. Kjosness; L. A. Rudolph, eds. 1980; brochure.

This booklet is illustrated and written by young people with cancer to help other childhood cancer patients with worries and concerns they may have. Twelve separate sections deal with the experiences that young people with cancer have in common and offer suggestions for coping with these.

Cost: free.

Source: The Children's Orthopedic Hospital and Medical Center
Division of Pediatric Hematology/Oncology
4800 Sand Point Way, N.E.
P.O. Box C5371
Seattle, WA 98105.
Telephone: (206) 634-5427.

Adolescent Information

1. Candlelighters Teenage Newsletter. [Serial]. Quarterly.

Written by and for adolescent cancer patients and the teenage siblings of cancer patients, the newsletter contains personal narratives as well as information

about programs and publications of interest to teenagers.

Cost: free.

Source: Teens Newsletter
Candlelighters
National Headquarters
123 C St., S.E.
Washington, DC 20003.
Telephone: (202) 544-1696.

2. Waiting for Johnny Miracle. Alice Bach. 1980. 240 pp; book.

This novel, written for adolescents about a 17-year-old girl with osteogenic sarcoma, centers on her experiences and feelings and those of her twin sister, parents, other family members, and friends. The novel depicts the family's efforts to continue life as normally as possible, and on hospitalization, clinic visits, and the feelings of other teenage cancer patients.

Cost: $8.95.

Order No. ISBN 0-06-020348-X.

Source: Harper and Row Publishers, Inc.
10 East 53rd St.
New York, NY 10022.

3. Too Old To Cry, Too Young To Die. Edith Pendleton. 1980. 177 pp; book.

This book records the experiences of 35 teenagers and young adults who have had cancer. It offers nine case studies of cancer patients and quotes and tips from these and other teenage patients on such subjects as cancer treatment, dealing with hospitalization and treatment staff, reactions of family members, returning to school, losing your hair, dating, relapse, and death.

Cost: $7.95.

Order No. ISBN 0-8407-4086-7.

Source: Thomas Nelson Publishers
P.O. Box 946
407 Seventh Ave., South
Nashville, TN 37203.

Sibling Information

1. When Your Brother or Sister Has Cancer. L. A. Rudolph. 1980. 22 pp; brochure.

Written for children from grade school age to early adolescence, this illustrated booklet is designed to help the brothers and sisters of cancer patients deal with their feelings. Some of the most common feelings a sibling may experience, such as anger, worry, sadness, guilt, and jealousy are discussed in order to reassure the child that these are normal reactions to having a sick child in the family.

Cost: free.

Source: The Children's Orthopedic Hospital and Medical Center
Division of Pediatric Hematology/Oncology
4800 Sand Point Way, N.E.
P.O. Box C5371
Seattle, WA 98105.
Telephone: (206) 634-5427.

Parent Information

General:

1. Candlelighters National Newsletter. [Serial]. Quarterly.

Information of interest to parents of childhood cancer patients is presented. Issues such as legislation to aid patients and their families, bibliographies, programs of national interest, overseas group activities, and general background on childhood cancer are included.

Cost: contact source.

Source: Candlelighters
National Headquarters
123 C St., S.E.
Washington, DC 20003.
Telephone: (202) 544-1696.

2. Childhood Cancer: A Pamphlet for Parents. S. E. Sallan; P. Newburger. 1978. 12 pp; brochure.

Facts about the diagnosis, treatment, and psychological aspects of childhood cancer are presented in a colorfully illustrated brochure for parents. Issues such as second opinions, drugs and their side effects, and what to tell the child, his siblings, and other people, are covered.

Cost: free; limited supply.

Source: Sidney Farber Cancer Institute
Cancer Control Program
44 Binney St.
Boston, MA 02115.
Telephone: (617) 732-3150.

3. Children Die Too. J. Johnson; S. M. Johnson. 1978. 16 pp; brochure.

The booklet briefly discusses emotions such as denial, guilt, anger, and depression which are commonly experienced by bereaved parents. Parents are advised on how to treat other family members and friends who were involved with the dead child.

Cost: contact source.

Source: Centering Corp.
Box 878
Council Bluffs, IA 51502.

4. Children in Hospitals, Inc. [Newsletter]. Quarterly. M K. Saphier, ed.

Support and advice are offered to parents of hospitalized children, with the goal of making the hospitalization as pleasant and nontraumatic as possible. The newsletter contains articles, reviews of books, pamphlets, movies, and media programs, members' letters, and announcements of society activities. Children in Hospitals publishes a listing of hospital policies regarding family contact in Boston area hospitals.

Cost: $4.

Source: Children in Hospitals, Inc.

31 Wilshire Park
Needham, MA 02192.

5. Choices: Realistic Alternatives in Cancer Treatment. M. Marra; E. Potts. 1980. 763 pp; book.

This handbook is written in lay terms for people with cancer, their families, and friends. All aspects of diagnosis and treatment are covered in a question and answer format. Individual chapters are devoted to each of the major cancer sites and one to childhood cancer, in addition to a section on coping with pain and an annotated list of cancer centers and research groups and other organizations which provide information and help to cancer patients.

Cost: $8.95.

Order No. ISBN 0-380-75291-3.

Source: Avon Books
959 Eighth Ave.
New York, NY 10019.

6. Coping at Home with Cancer. For Parents, by a Parent. N. Cottrell. 1977. 24 pp; brochure.

Advice is offered to other parents of childhood cancer patients by parents of a two-year-old boy who died of a brain tumor at home. Their personal account emphasizes ways in which parents can care for terminally ill children at home, giving both nursing care and emotional support. Practical hints are summarized, including management of visits to the hospital, preparation of oral medications, and organizing recreational activities.

Cost: $1.00.

Source: The Children's Hospital, Inc.
ATT: CHA
345 N. Smith Ave.
St. Paul, MN 55102.
Telephone: (612) 298-8666.

7. Coping with Prolonged Health Impairment in Your Child. A. T. McCollum. 1975. 240 pp; monograph.

Based in part on experiences with patients and their families in the Yale Children's Clinical Research Center and the Yale Cystic Fibrosis Program, the book was prepared to help families enhance the quality of life of their child who is afflicted with a prolonged physical disorder. Directives are given on how to help the child understand his value as a human being and how to help him form satisfying relationships and develop his capabilities as fully as possible. General guidelines for anticipating needs and planning solutions are discussed; and the composite experiences of families who have coped with a child's illness are made available. The ways professionals can offer significant help

to the child and family are described.

Cost: $11.50.

Order No. ISBN 0-316-54185-0.

Source: Little, Brown and Co.
200 West St.
Waltham, MA 02154.
Telephone: (617) 227-0730.

8. Emotional Aspects of Childhood Cancer and Leukemia: A Handbook for Parents. J. J. Spinetta; P. D. Spinetta; F. Kung; D. B. Schwartz. 1976. 21 pp; brochure.

The emotions often experienced by parents whose children have cancer are discussed and the demands of illness upon a family are considered. The booklet describes in some detail the initial reaction to diagnosis, children's concepts of death, hospitalization, home care, and methods of communicating with the child.

Cost: $0.75.

Source: Leukemia Society of America, Inc.
San Diego Chapter
326 Broadway, Mezzanine Suite
San Diego, CA 92101.
Telephone: (714) 239-7781.

9. Home Care for Dying Children: A Manual for Parents. D. G. Moldow; I M. Martinson. 1979. 123 pp; manual.

The first chapter describes the concept of home care and explains the situations in which it is the most practical kind of care. Further discussion includes ideas about treatment, pain relief, the importance of enjoying life as much as possible, and the provisions necessary for home care. There is information on medications, and on prevention and control of peripheral medical problems.

Cost: $4.00.

Source: School of Nursing
Univ. of Minnesota
3313 Powell Hall
500 Essex St., SE
Minneapolis, MN 55455.
Telephone: (612) 376-1430.

10. Living in a Strange World. E. F. Shimberg. 1979. 32 pp; brochure.

The most common forms of childhood cancer are described and current treatment techniques are briefly explained. The importance of maintaining "normalcy" in the home and at school is stressed. A glossary, a list of community resources, and a bibliography are appended.

Cost: free to parents and physicians in Florida.

Source: American Cancer Society, Florida Div.
1001 South MacDill Ave.
Tampa, FL 33609.
Telephone: (813) 253-0541.

11. Living One Day At a Time (LODAT). Oncology Handbook for Parents. B. Lederer. 1977. 56 pp; brochure.

Prepared for the organization "Living One Day At a Time" (LODAT), the booklet can help parents of children with cancer cope with the psychological and practical problems of the illness. Information is provided on the biology of leukemia and common childhood tumors, and on forms of treatment and responses, including a table of commonly used drugs and their side effects. Advice is given on how to: relay medical instructions to the patient, handle relatives and friends, prepare for out- or in-patient visits to the hospital, and pay bills. Also included are a glossary of relevant medical terms, a bibliography of materials for both parents and children, names of organizations that can help parents of children with cancer, and a brief profile of LODAT, a Milwaukee-based group founded in 1975.

Cost: free.

Source: LODAT
P.O. Box 13154
Milwaukee, WI 53213.
Telephone: (414) 461-5347.

12. Organization and Information Handbook for Parents Groups: 1977-1978. 49 pp; brochure and sample forms.

Parents of childhood cancer patients are instructed on how to form self-help groups and develop other outreach activities. Methods for recruiting members, organizing meetings, developing promotional materials, and coordinating chapter efforts with the national movement are explained. Information on linking with community resources and such non-profit agencies as the American Cancer Society is also provided.

Cost: contact source.

Source: Candlelighters
National Headquarters
123 C St., S.E.
Washington, DC 20003.
Telephone: (202) 544-1696.

13. Parents: When Your Preschooler is Hospitalized, Consider Yourself an Important Member of the Medical Team. M. K. Saphier. *Children in Hospitals, Inc. Newsletter:* 1-8, Spring 1977.

The author analyzes the emotional trauma of separation and its effects on the hospitalized preschooler's relationship with his family. Parents are urged to avoid separation whenever possible. If they are unable to stay with the child constantly, the article offers alternative strategies to alleviate the child's anxiety during periods of absence. Changes in hospital procedure to incorporate the parent into the patient care team are also recommended, and

parents are advised of their rights in a hospital situation. A list of references is included.

Cost. contact source.

Source: Children in Hospitals, Inc.
31 Wilshire Park
Needham, MA 02192.

14. Pediatric Oncology Bibliography. M. Sachs; P. Tharp, comps. 1980. 19 pp; bibliography.

Book, journal articles, and audiovisual materials are listed in this resource guide prepared for pediatric oncology patients, their families and health care professionals. Divided by general subject areas, the bibliography includes a section on agencies and organizations that provide information on cancer.

Cost: free.

Source: At-Home Rehabilitation Program
University Hospitals Cancer Center
2074 Abington Rd.
Cleveland, OH 44106.
Telephone: (216) 444-3783.

15. Radiation Therapy: A Family Handbook. C. U. Marshall; P. Flumnerfelt. 37 pp; brochure.

This illustrated handbook attempts to answer those questions concerning treatment of the pediatric cancer patient that are most frequently asked by patients and their families. The first chapter briefly explains the function of each member of the oncology team, while subsequent chapters cover all aspects of radiation treatment including the development of a protocol, equipment used, and possible side effects of therapy. A glossary is appended and detailed information is provided about Indiana University School of Medicine hospital facilities.

Cost: $2.50 plus postage and handling.

Source: Indiana University School of Medicine
Radiation Oncology Dept.
1100 West Michigan St.
Indianapolis, IN 46223.
Telephone: (317) 264-2524.

16. Students with Cancer: A Resource for the Educator. 1980. 24 pp; brochure.

This booklet was prepared for educators, to help answer their questions about handling children with cancer in the school setting. It explains the disease, its treatment and effects, as well as suggests approaches for dealing with the child, classmates and parents. A list of sources of additional information is included, as are bibliographies about cancer for young people and educators.

Cost: free.

Order No. NIH 80-2086.

Source: National Cancer Institute
Office of Cancer Communications
Bldg. 31, Rm. 10A18
9000 Rockville Pike
Bethesda, MD 20205.

17. Talking to Children About Death. 1979. 16 pp; brochure.

Guidelines are suggested for communicating with children about death. Various situations in which the child may ask questions about death are considered, ranging from a news report on television to the death of a family member.

Cost: $1.50.

Order No. DHEW (ADM) 79-838.

Source: Superintendent of Documents
U.S. Government Printing Office
Washington, DC 20402.
Telephone: (202) 783-3238.

18. The Bereaved Parent. H. S. Schiff. 1977. 146 pp; book.

The Bereaved Parent offers advice to parents who are facing the death of a child as well as those whose child has already died. It covers the day-to-day decisions that must be made, such as funeral arrangements, and considers the problems involved in rebuilding family relationships and coping with delayed reactions.

Cost: $1.98.

Source: Crown Publishers, Inc.
One Park Ave.
New York, NY 10016.
Telephone: (212) 532-9200.

19. What You Need to Know . . . 1979. Series; brochures.

Recent advances in the diagnosis and treatment of cancer are described in brochures developed for cancer patients and their families. Each contains information on the nature of cancer, sources of assistance, areas of research, and definitions of medical terms. One booklet covers cancer in a general fashion while six others address forms of cancer most commonly seen in children: Brain, Bone, Hodgkin's Disease, Non-Hodgkin's Lymphoma, Childhood Leukemia, and Wilm's Tumor.

Cost: free.

Source: National Cancer Institute
Office of Cancer Communications
Bldg. 31, Rm. 10A18
9000 Rockville Pike
Bethesda, MD 20205.

20. When Your Child Goes to the Hospital. 1977. 8 pp; brochure.

Mister Rogers, a popular children's television personality, suggests ways in which parents can help their children master their feelings about the hospital experience. Parents are encouraged to participate in the care of their child.

Cost: $12/100.

Source: Family Communications
Let's Talk About It
4802 Fifth Ave.
Pittsburgh, PA 15213.
Telephone: (412) 687-2990.

21. When Your Child Goes to the Hospital. P. D. Pizzo. 1976. 36 pp; brochure.

Designed to help parents cope with their child's hospitalization, the publication stresses the importance of psychologically preparing both themselves and the child. Recommended methods include choosing a doctor and a hospital; a prehospitalization visit with the child; and giving the child simple, honest answers to his questions. Suggested readings and questions to ask about the hospital are appended.

Cost: $0.85.

Order No. DHEW 76-30092; GPO 017-091-00217-7.

Source: Superintendent of Documents
U.S. Government Printing Office
Washington, DC 20402.
Telephone: (202) 783-3238.

Leukemia:

22. Acute Lymphoblastic Leukemia (ALL) of Childhood: A Pamphlet for Parents. S. E. Sallan. 1975. 8 pp; brochure.

Directed to parents, the pamphlet presents basic information about acute lymphoblastic leukemia in children, its diagnosis and treatment, and the emotional implications for the child and the family. A glossary at the end explains technical terms.

Cost: free.

Source: Sidney Farber Cancer Institute
44 Binney St.
Boston, MA 02115.
Telephone: (617) 732-3000.

23. Childhood Leukemia: A Pamphlet for Parents. B. Friedman; M. Karon; G. Goldsmith. Rev. 1972. 26 pp; brochure.

General aspects of childhood leukemia, its treatment, and common psychological reactions are discussed in this pamphlet.

Cost: free.

Source: National Cancer Institute
Office of Cancer Communications
Bldg. 31, Rm. 10A18
9000 Rockville Pike
Bethesda, MD 20205.

24. Childhood Leukemia, the Family Disease. K. Briscoe. 11 pp; typescript.

Most of the tension, fears, fantasies, and emotional strain that affect every member of the family can be alleviated by faith, hope, and open and honest communication, according to a parent of a child who died of leukemia. Among the specific problems dis-

cussed are: fear of losing the child; communication breakdowns; feelings of resentment and neglect of healthy family members; guilt; extra attention for the ill child; overprotection and overpermissiveness; emotional stability; being open with the child about depression, diagnosis, prognosis, and treatment; hospital routine; and parent discussion groups.

Cost: free.

Source: American Cancer Society
Montgomery County Unit
344 University Blvd. W.
Silver Spring, MD 20910.
Telephone: (301) 593-3055.

25. Leukemia: A Guide to the Management of the Disease. G. Taylor. 22 pp; brochure.

The brochure, an adaptation of a chapter from "Experiences with Childhood Cancer," discusses both the emotional crises faced by the parents and siblings of a child with a life-threatening illness and the management of these crises by health care professionals. The roles and responsibilities of nurses, doctors, and others are outlined, and supportive agencies are listed.

Cost: free.

Source: Leukemia Society of America, Inc.
National Headquarters
800 Second Ave.
New York, NY 10017.
Telephone: (212) 573-8484.

26. Leukemia and the Family. 1977. 66 pp; brochure.

This brochure focuses on the emotional and social effects of childhood leukemia on both patient and family. Some practical and technical information directly related to the disease (such as home nursing care and drugs employed to treat leukemia) is presented, but the brochure is mainly devoted to such problems as social isolation, marital stress, emotional stress endured by the leukemic child, and various reactions to the diagnosis. Line drawings sympathetically illustrate the text.

Cost: $1.75.

Source: Association for the Study of Childhood Cancer
MCV Station
Box 762
Richmond, VA 23298.

27. The Leukemic Child. M. Sherman. 1976. 80 pp; book.

A mother (who is also a journalist) gives an account of her young daughter's struggle with acute lymphocytic leukemia, which took her life after two and one-half years. She describes the diagnosis and treatment, the pattern of remissions and relapses, treatment side effects, and periods of hospitalization. Perhaps most central to the book—and of great value to others who may undergo similar experiences—are the sections showing the ways in which

the child, her two sisters, and the mother coped with the emotional and psychological impact of chronic illness and, finally, death.

Cost: free

Source: National Cancer Institute
Office of Cancer Communications
Bldg. 31, Rm. 10A18
9000 Rockville Pike
Bethesda, MD 20205.

28. Parents' Handbook on Leukemia. E. W. Schweers; P. Farnes; E. N. Forman. 1977. 60 pp; brochure.

Parents of leukemic children are provided with medical and practical information to help them cope with their child's disease. Topics covered include oncology clinic procedures, drug actions, related medical questions, and parental roles and problems. A glossary is provided.

Cost: free.

Order No. 4556.

Source: American Cancer Society, local units.

Nutrition:

29. Diet and Nutrition: A Resource for Parents of Children with Cancer. 1979. 57 pp; brochure.

This handbook, designed for the parents of children with cancer, is intended to serve as a source of information on all aspects of diet and nutrition as they relate to the pediatric cancer patient. Numerous suggestions are offered for coping with day-to-day nutritional problems that may arise as a result of the side effects of various cancer treatments. One section of the guide contains colorful, illustrated diet sheets that can be removed and displayed for handy reference. A poster entitled "How to Build a Stronger Kid" is also included. It lists the best food sources for vitamins, minerals, proteins, carbohydrates, and fats, and describes what roles these substances play in the formation of a healthy body.

Cost: free.

Order No. NIH 80-2038.

Source: National Cancer Institute
Office of Cancer Communications
Bldg. 31, Rm. 10A18
9000 Rockville Pike
Bethesda, MD 20205.

30. Feeding the Sick Child. M. Sherman. 1976. 68 pp; booklet.

Sick children frequently reject nourishing food because of odor, texture, color, or sweetness. Therapy causes such side effects as loss of appetite, nausea, and vomiting. A relaxed, open, and innovative attitude toward the child's nutritional needs may alleviate these problems. Guidelines to good nutrition are included, along with recipes and a list of child-oriented cookbooks.

Cost: free.

Order No. DHEW (NIH) 77-795.

Source: National Cancer Institute
Office of Cancer Communications
Bldg. 31, Rm. 10A18
9000 Rockville Pike
Bethesda, MD 20205.

Personal Accounts:

31. The Last Day of April. N. Roach. 1974. 40 pp; brochure.

The mother of a leukemia patient recounts the experiences of the family during the several years of therapy, remissions, relapses, and eventual death of their child. The account endeavors to show how the parents dealt with both their own and their daughter's emotional problems and how the family successfully coped with the child's death. An introduction by a professor of pediatrics underlines the value of this personal account in helping parents of children with malignant disease.

Cost: free.

Source: American Cancer Society, local units.

32. Scott Was Here. E. Ipswitch. 1979. 210 pp; book.

A mother describes the courage of her 15-year-old son, who fought for his life against Hodgkin's disease. Using a journal kept by her son during his illness, the mother discusses how the boy coped with diagnosis, treatment, and death.

Cost: $8.95.

Source: Delacorte Press
1 Dag Hammarskjold Plaza
245 E. 47th St.
New York, NY 10017.
Telephone: (212) 832-7300.

33. Shannon: A Book for Parents of Children with Leukemia. E. L. Johnson; M. Miller. 1975. 132 pp; book.

In this narrative, the unusual lifestyle and emotions of a little girl with leukemia are revealed. In alternating chapters, Dr. Johnson, an expert in pediatric cancer, and Mary Miller, Shannon's grandmother, describe the clinical and human sides of cancer treatment. Information about the diagnosis, treatment and side effects, and emotional implications of childhood leukemia is presented in a concise, readable form.

Cost: $6.95

Source: Hawthorn Books, Inc.
260 Madison Ave.
New York, NY 10016.
Telephone: (212) 725-7740.

Other materials on cancer are available from the National Cancer Institute at no charge. To receive information on these materials, write: National Cancer Institute
Office of Cancer Communications
Building 31, Room 10A18
9000 Rockville Pike
Bethesda, MD 20205

* U.S. GOVERNMENT PRINTING OFFICE: 1982 O - 365-345 : QL 3

Drug Chart

Developed by Sondra R. Tabor, R.N., M.N., Clinical Specialist, Amie Karen Cancer Center, Division of Pediatric Hematology/Oncology, Department of Pediatrics, Cedars-Sinai Medical Center, UCLA, Los Angeles, CA 90048.

KEY: P.O. – Oral; I.M. – Intramuscularly; I.V. – Intravenously; I.T. – Intrathecally (into spinal canal); S.Q. – Subcutaneously; C – Commonly seen; O – Occasionally seen; R – Rare

Drug	Common Route(s) of Administration	Description	Side Effects	Frequency of Effects
Actinomycin *(Dactinomycin, Cosmegan, Act-0)*	I.V.	Clear, yellow liquid	• Nausea and vomiting	C
			• Bone marrow depression	C
			• Hair loss	O
			• Mental depression	O
			• Skin eruptions (Acne)	O
			• Fever, malaise	R
			• Causes tissue burns if it infiltrates	
Adriamycin *(Doxorubicin)*	I.V.	Clear, red liquid	• Pink urine (not blood)	C
			• Nausea and vomiting	C
			• Bone marrow depression	C
			• Hair loss	C
			• Sore mouth	O
			• Fever	O
			• Causes tissue burns if it infiltrates	
Ara-C *(Cytosar, Cytosine Arabinoside, Cytarabine)*	I.V. S.Q. I.T.	Clear, colorless liquid	• Nausea and vomiting	C
			• Loss of appetite	C
			• Abdominal cramps and diarrhea	O
			• Sore throat or mouth	O
			• Bone marrow depression	R
			• Headache	R
BCNU *(Carmustine)*	I.V.	Clear, colorless liquid	• Burning along vein of injection	C
			• Bone marrow depression (3-4 weeks after injection)	C
			• Nausea and vomiting (1-4 hours after dose)	C
Bleomycin *(Blenoxane, Bleo)*	I.V. I.M. S.Q.	Clear, colorless liquid	• Nausea and vomiting	C
			• Fever, chills (at once)	C
			• Mouth ulcers	C
			• Loss of appetite and weight	C
			• Hair loss	C
			• Allergic reaction (may be severe, 3-5 hours after dose)	R
			• Liver and kidney damage	R
CCNU *(Lomustine)*	P.O.	Capsules: 10, 40, and 100 mg	• Nausea and vomiting	C
			• Bone marrow depression (3-6 weeks after dose)	C
NOTE: Give with sip of water on empty stomach; then nothing to eat or drink for 2 hours.				
Chlorambucil *(Leukeran)*	P.O.	White, sugar-coated tablet – 2 mg	• Bone marrow depression (2-3 weeks after dose)	
			• Nausea and vomiting	
			• Loss of appetite	
Cis-Platinum *(investigational)*	I.V.	Clear, colorless liquid	(As far as presently known)	
			• Nausea and vomiting (may be severe)	C
			• Loss of appetite	C
			• Bone marrow depression	C
			• Kidney damage	R
Cytoxan *(Cyclophosphamide, CTX, CPM)*	P.O. I.V.	Medium or large white pill with blue flecks: 25 and 50 mg	• Bone marrow depression	C
			• Nausea and vomiting	C
			• Loss of appetite	C
			• Hair loss	C
		Clear, colorless liquid	• Cystitis with blood in urine	O
			• Sore mouth	O
			• Diarrhea	R
Daunomycin *(Rubidomycin, DMN, Daunorubicin)*	I.V.	Clear, red liquid	• Pink urine (not blood)	C
			• Nausea and vomiting	C
			• Bone marrow depression	C
			• Hair loss	C
			• Mouth ulcers	O
			• Fever	O
			• Causes tissue burns if it infiltrates	
OTIC *(Dacarbazine)*	I.V.	Clear, yellowish liquid	• Bone marrow depression	C
			• Nausea and vomiting	O
			• Burning along vein of injection	O
			• Fever, achiness	O
5-Fluorouracil *(5-FU)*	I.V. P.O.	Clear, colorless liquid	• Nausea and vomiting	C
			• Bone marrow depression (9-14 days after dose)	C
			• Diarrhea	O
			• Mouth ulcers	O
			• Hair loss	R
			• Skin rash	R
			• Liver damage	R
			• Causes tissue burns if it infiltrates	
Hydroxyurea *(Hydrea, HU)*	P.O.	Green and pink capsule – 500 mg	• Nausea and vomiting	C
			• Bone marrow depression	C
			• Mouth ulcers	O
			• Hair loss	R
			• Headache, dizziness	R
			• Skin rash	R
L-Asparaginase *(L-Asp, Elspar)*	I.M. S.Q. I.V.	Thick, colorless liquid	• Loss of appetite	O
			• Nausea and vomiting	O
			• Fever	O
			• Allergic reactions (may be severe)	R
			• Liver or pancreas dysfunction (abdominal pain, elevated blood sugar, increased thirst)	R
6-Mercaptopurine *(Purinethol, 6 MP)*	P.O.	Large white tablet – 50 mg	• Bone marrow depression	C
			• Loss of appetite	O
			• Nausea and vomiting	O
			• Diarrhea	R
			• Fever	R
			• Jaundice	R
			• Sore mouth	R
Methotrexate *(Amethopterin, MTX)*	P.O. I.V. I.M. I.T.	Small yellow tablet – 2.5 mg; Clear, yellow liquid	• Oral ulcers (sores)	C
			• Bone marrow depression	C
			• Nausea and vomiting	C
			• Loss of appetite	O
			• Hair loss	O
			• Diarrhea	R
			• Rashes	R
			• Jaundice	R
NOTE: While on Methotrexate, the following should be avoided: tetracyclines, A vitamins, alcohol, chloramphenicol.				
Mithramycin *(Mithracin)*	I.V.	Clear, colorless liquid	• Nausea and vomiting	C
			• Loss of appetite	C
			• Bone marrow depression	C
			• Mouth ulcers	C
			• Fever, drowsiness, weakness	O
			• Facial flushing	O
			• Skin rash	O
			• Unusual bleeding (may be severe)	R
			• Liver and kidney damage	R
			• Causes tissue damage if it infiltrates	
Nitrogen mustard *(HN_2, Mustargen, Mechlorethamine)*	I.V.	Clear, yellowish liquid	• Nausea and vomiting	C
			• Diarrhea	O
			• Skin rash	R
			• Causes tissue burns if it infiltrates	
Prednisone *(a steroid)*	P.O.	White pill: 1, 5, 20, and 50 mg	• Weight gain, rounded face	C
			• Stomach irritation	O
			• Suppression of fever or other signs of infection or inflammation	O
			• Emotional changes	O
NOTE: Must be tapered slowly if taken for longer than 7-10 days.				
Hydrocortisone *(Solu-cortef)* *(a steroid)*	I.V.	Clear, colorless liquid	• Elevated blood pressure	R
			• Muscle weakness	R
			• Increased thirst, increased urination, elevated blood sugar	R
Procarbazine *(Matulane)*	P.O.	White capsule – 50 mg	• Nausea and vomiting	C
			• Bone marrow depression	C
			• Diarrhea/constipation	O
			• Dry mouth	O
			• Fever/chills	O
			• Skin rash	R
			• Headache, dizziness	R
NOTE: While on Procarbazine, avoid antihistamines, barbiturates, narcotics, antidepressants, alcohol, ripe cheese, bananas.				
6-Thioquanine *(6-TG)*	P.O.	Small, tan tablet – 40 mg	• Nausea and vomiting	C
			• Sore mouth	C
			• Bone marrow depression	C
Vincristine *(Oncovin, VCR)*	I.V.	Clear, colorless liquid	• Jaw pain, pain in limbs or abdomen	O
			• Constipation	O
			• Tingling in hands or feet	O
Vinblastine			• Loss of appetite	O
			• Leg weakness	O
Vindesine *(VND)*			• Causes tissue burns if it infiltrates	
VM-26	I.V.	Clear, colorless liquid	(As far as presently known)	
VP-16 *(investigational)*			• Bone marrow depression	C
			• Hair loss	O
			• Nausea and vomiting (mild)	O
			• Diarrhea	O
			• Allergic reaction	R
			• Causes tissue burns if it infiltrates	